STIGMA AND RESILIENCE: LIVED EXPERIENCES OF PEOPLE WITH HIV IN A NORTHERN COMMUNITY

by

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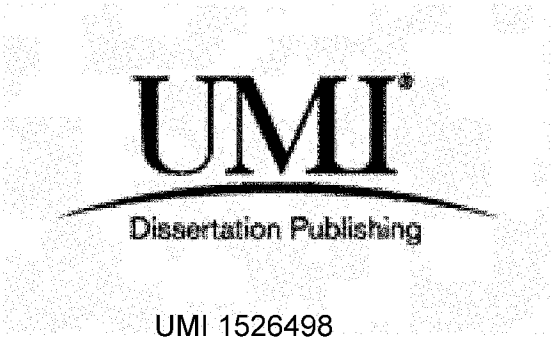

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Abstract

Stigma is a reality for millions of individuals who are living with HIV/AIDS and is accompanied with many challenges, however individuals are resilient in spite of the negative impacts of stigma. The purpose of this research was to explore and highlight the lived experience of people living with HIV-related stigma in Prince George, secondly, to understand the impacts of stigma, and thirdly, to identify the ways in which those living with HIV/AIDS respond to stigma. The research draws on hermeneutics phenomenology as this enables the exploration of participants' experiences of stigma and resilience. Findings that have emerged from the thematic analysis have shown that stigma both enacted and felt is still prevalent in the lives of the participants. Also, participants' experienced various challenges such as: mental health problems, substance abuse, financial problems and the lack of relationships. However, despite these challenges, participants reported feeling optimistic and hopeful as well as experiencing spiritual growth, finding a sense of purpose while living with their diagnosis. Overall participants in the study are adapting to their hardship and choosing not to be victims of HIV but survivors and fighters.

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Dedication

I would like to dedicate this thesis to all seven participants in this study. Thanks for sharing your passion, joy, strength, resilience and allowing me the opportunity to be a part of your journey. I would also like to acknowledge a special friend who sadly passed away before the start of this study. Your memories will forever live on. To all the participants love and thanks forever, your stories have touched my heart and serve to inspire and encourage me.

Acknowledgement

Overall this process has been a very hard and daunting experience, one filled with joy, sadness, passion and resilience. Thanks to my heavenly Father for motivation and inner strength to never give up.

Thanks to my supervisors Dr. Josée Lavoie and Dr. Tina Fraser and committee member Dr. Theresa Healy for all your words of encouragement and your guidance in this process. Thanks much for your patience, it was much appreciated. Also, I would like to extend thanks to my external committee member Dr. Davina Banner-Lukaris.

I am forever indebted to my Parents, Renel and Erselin, calling daily providing words of encouragement and love. Hearing your words of encouragement was music to my soul.

I am forever grateful, to the staff and members of Positive Living North: No khēyoh t'sih'en t'sehena Society. I am so thankful for your support, love, patience and help. Thanks for the opportunity to volunteer at your organization and making me feel at home.

This thesis would not be possible without the physical, emotional, and mental support of all my wonderful friends. Thanks to Adrian, Quinn, and Robert. Thanks for listening to all my complaints and for being there when I needed a shoulder to cry on. Best friends are indeed better than pocket money. Love you all.

Thanks All and One Love.

Chapter One: Introduction

On April 7, 2008 an article was posted on the CBC News website, which read:

> Seven members of Positive Living North were flying to a conference in Vancouver last week but their flight was delayed for an hour after an airport security guard raised concerns about their "diseases" with WestJet flight staff . . . The airport security guard had asked for a wipe down because he said he knew people in the group had "diseases." "He [the security guard] said that he had recognized one of the members . . . He said he knew this person has diseases and that he was trying to keep the staff and people safe in the aircraft" . . . Members of group said they had been publicly humiliated. "I was disgusted . . . I just thought, 'Who the hell do you think you are? You don't even know me," said one of the person living with AIDS (CBC News, 2008, para. 2).

Stigma is a reality for millions of individuals who are living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) (International Centre for Research on Women, 2010). Despite countless programs, and efforts by educational, developmental and governmental agencies working to fight the spread of HIV/AIDS, there remains a very real and devastating reality that HIV/AIDS has become one of the leading cause of death in many countries worldwide (World Health Organization, 2013). According to Mahajan and colleagues (Mahajan et al., 2008), one of the main targets propelling the spread of HIV is stigma. Equally significant but most often ignored, is the social impact of HIV/AIDS-related stigma and discrimination. Stigma is not new to public health, nor is it unique to HIV/AIDS. History provides an unfortunate abundance of examples of "prejudice, discounting, discrediting, and discrimination" (Herek & Capitanio, 1998).

According to the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF), HIV is a biologically complex virus but its complexity is pale in comparison to the complexity of the social forces that is involved in the production and reproduction of stigma in relation to HIV/AIDS (as cited in Mawar, Sahay, Pandit & Mahajan, 2005). Though stigma is just one aspect of the socio-psychological perspective of HIV/AIDS, addressing the issue is arguably one of the most important components in curtailing the spread of HIV and its impact on the lives of those significantly affected. Stigma and discrimination impede both the willingness and ability to adopt HIV preventive behavior (Sweendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). Stigma has the potential to limit prevention efforts (AIDS Alert, 2002; Des Jarlais, Galea, Tracy, Tross, & Vlahov, 2006; Herek & Capitanio, 1998). It may act as a barrier to diagnosis (De Bruyn, 1998; Link & Phelan, 2003), induce psychological stress, and result in a lack of openness to access health services (DeBruyn, 1998; Link & Phelan, 2003). Additionally, stigma associated with an illness influences both the clinical course of the condition and outcomes (DeBruyn, 1998; Link & Phelan, 2003) which can exacerbate a person's condition.

Although most stigma research highlights deterimental effects, the question one needs to ask is how do individuals 'bounce back' and be resilient in spite of the negative impacts of stigma. The concept of resilience acknowledges limits in the face of challenges, yet it focuses on the capacity of individuals to adapt to these limits and still achieve a full life (Windle, 2011). Resilience does not represent an endpoint on a continuum. Resilience has been conceptualized as a dynamic developmental process in which there may be many stepwise iterations moving gradually toward a reconstituted sense of wellness (Windle, 2011). It also encompasses the attainment of positive adaptation within the context of significant threat, severe adversity, or trauma. Most literature focuses on identifying the harmful impacts of stigma. Very limited

research exists looking at resilience emerging as a result of stigma related to HIV (Smith, 2012; Shih, 2004). This research will not only focus on the lived experiences of stigma and its impact, but will also look at ways in which individuals experience stigma and nevertheless continue to respond positively to the management of their illness.

Background

HIV/AIDS epidemic has created a terrible burden for individuals, families and communities worldwide and continues to remain a major public health crisis. Despite some progress made today, the HIV pandemic remains the most serious infectious disease challenge to public health (Victoria et al., 2009). Approximately 34 million people worldwide are living with HIV (UNAIDS, 2012). In 2011, 2.5 million people were newly infected with HIV while 1.7 million people died of an AIDS-related illness (UNAIDS, Global Fact Sheet, 2012). In 2008, an estimated 65,000 Canadians were living with HIV and 16,900 individuals were unaware of their HIV infection because they had not been tested (Canadian AIDS Treatment Information Exchange [CATIE], 2010). Although the number of new cases has remained stable since 2008, the number of HIV cases continues to increase, due to new treatments, improved access to antiretroviral drugs and longer survival rates of people living with HIV (Public Health Agency of Canada [PHAC], 2012).

Stigma has often been viewed as a phenomenon that exists in the background of the HIV/AIDS epidemic rather than an issue warranted to be studied in its own right (Emlet, 2005). As early as 1987, Jonathan Mann, Director of the World Health Organization's Global programme on AIDS identified three epidemics: 1) HIV infection, 2) the AIDS epidemic itself, and 3) HIV/AIDS stigma. He describes the latter as potentially the most explosive of the three epidemics (as cited in Stein, 2003). Fifteen years later, Peter Piot, Executive Director of

UNAIDS, prioritized stigma as the first on the list of five of the most pressing items on the organization agenda. This is due to the fact that stigma remains as the "roadblock to concerted action, whether at the local community, national or global level, so action against stigma ramifies across every single aspect of HIV work" (as cited in Parker & Aggleton, 2003, p. 6). According to UN Secretary-General Ban Ki Moon:

> [Stigma] is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world (The Washington Times, 2008, p. 1).

The experience of stigma has been associated with clinical depression, shame, guilt, fear, anger, lesser chances of disclosure, and lower adherence to a medication regime (Fresko, 2001; Vanable et al., 2006). Also, stigma often leads to discrimination and this, in turn, can lead to human rights violations for people living with HIV/AIDS and their families (UNAIDS, 2003). Such behaviors hamper prevention and care efforts for people living with HIV by sustaining silence and denial about their HIV/AIDS. This may reinforce the marginalization of people living with HIV/AIDS particularly among those who are already vulnerable such as sex workers, gays and injection drug users. Therefore, the problems experienced, and resilience-informed strategies adopted, by those living with HIV-related stigma, are important issues requiring more in-depth research.

In the past, researchers traditionally focused on the negative effects of stressful situations to better understand physical and mental illness. While there have been numerous studies on

resiliency in trauma recovery and childhood resiliency, research addressing individuals lived experience as it relates to HIV and stigma is severely lacking (Bonanno, 2004). Resilience is the capacity of a person to endure hardship and having the ability to bounce back (Bonanno, 2004; Tugade &Fredrickson, 2004). Resilience has been identified as the ability to maintain a healthy level of psychological and physical functioning during periods of violent or life threatening situations (Bonanno, 2004). According to Bonanno (2005), some people are unable to recover from acute stress or traumas. However, others manage to endure the "traumatic events remarkably well, with little disruption in their ability to function at work or in close relationships; they seem to move on to new challenges with apparent ease" (p. 6). Studies have reported that resilience to trauma and the makeup of the phenomenon is a poorly understood phenomenon (Bonanno, 2005). Understanding resilience requires an exploration from a survivor's perspective, from the onset of hardship throughout recovery. This is the focus of this study.

Purpose of Study

The purpose of this research was to explore and highlight the lived experience of persons living with HIV (PLWHA) related stigma in Prince George; secondly, to understand the impacts of stigma; thirdly, to identify ways in which those living with HIV/AIDS respond to stigma. Specific questions include:

1) What are the experiences of people living with HIV/AIDS as it relates to stigma?

2) What are the impacts of stigma on individuals' lives?

3) How do people respond to stigma?

4) In what ways have the individual's response to stigma (positive and negative) impacted their

self-care?

Significance of Study

As an illness, HIV may elicit profound stigma and is still the most important issue that hinders HIV prevention. In addition, having the knowledge of the phenomenon of HIV/AIDS stigma is important for family members, community and health professionals because it has serious consequences and has the potential to influence health and health seeking behaviors of individuals infected and affected by HIV/AIDS. Although, each individual living in Prince George experienced stigma differently, research findings shows there are commonalities that exists. Therefore, understanding individual's experience of stigma may assist practitioners, counsellors in the development of programs and interventions focused on meeting the needs of PLWHA, and identify possible solutions to reduce stigma.

Likewise, previous research looked at stigma in terms of measurement of stigma components and processes, theory and negative consequences, with limited research looking at positive responses to stigma in terms of resilience, adaptation to circumstances and personal growth. Resiliency, is important because it refers to the phenomenon of successfully dealing with significant threats presented in individual's lives. Threats in this sense may negatively impact on PLWHA development, health, happiness and overall quality of life. Successfully navigating such threats is vital for the empowerment and personal growth of the individual and ultimately therefore – their overall health and well-being. Therefore, an understanding of these information will allow service providers and counselors the opportunity to assist individuals develop resilient abilities; acquire internal and external assets, and supports that will help them overcome adversity and live an improved quality of life and experience improved health.

Motivations for Conducting the Study

The study of resilience in the face of HIV/AIDS-related stigma and discrimination has appealed to me because of my personal experiences in dealing with stigma attached to being an obese, black Jamaican man. My social labels and experiences add layers to my own personal fears that are related to HIV/AIDS. I have experienced working with HIV positive individuals, and hearing their stories and experiences have left an indelible mark on me as an individual.

I was born in a large city in the parish of St Andrew in Jamaica where I spent most of my life before immigrating to Canada. I attended private schools, and had the privilege of obtaining a BSc degree in medical technology. I consider myself a very religious person who holds very conservative Christian worldviews. I had very little experience and thoughts to HIV before my job at the blood bank in 2007. Although I may never fully understand what it is really like for a person to live with HIV, I can empathized with them on what it is like to be stigmatized, fearful and ashamed.

In my own case, I still remember waiting patiently and anxiously hoping that the HIV test would be negative. While conducting a routine blood grouping test, a lab accident occurred where a donor blood sample splattered over my face. Also, I was stuck with the tube containing the patient's sample. I still remember crying and praying that the blood would be HIV negative. I thought that I could not possibly live with a positive diagnosis. To me, this would be the end of my world. The patient sample was negative; I could now breathe a sigh of relief. As it took time for HIV to be detected, I was advised by my doctor to take post-exposure prophylaxis drug as a safety precaution. For one month I experienced the side effects of the medication. There were days I felt like throwing away the pills, but the support and encouragement of my parents and my extended family kept me going.

The above incident made me realized that I could not handle another form of stigma. I thought I would not be able to survive. I became paranoid, even though the result showed that I was HIV negative, I got tested every month for the next 18 months. During this period it caused me to reminisce on my past prejudices related to those living with HIV. I remember one incident very vividly; I had discriminated against a lady at my church who was living with HIV. I hardly spoke to her and avoided having conversations with this person. Hearing about her death, I had no remorse: in my mind I felt that she deserved death, since she contracted the virus while working as a sex worker. However, after interacting with a few PLWHA and after my experience in the lab, I saw my own faults and biases which made me realize I am only doing harm to these individuals, and needed to become a part of the solution. The thought of being HIV positive made me feel hopeless. However, millions of people are HIV positive and as I think about these individuals, various questions I ponder such as: how do people living with HIV survive in the light of stigma and discrimination, what are their subjective experiences and how can they cope in light of the impacts of ongoing stigma and discrimination?

In 2011, I did voluntary work at Positive Living North: No khēyoh t'sih'en t'sehena Society [1] (PLN), I was surprised to encounter people whose stories were of survival more than sickness, accomplishments and determination more than destitution. What I saw at PLN was a group world of transformed people trying to live positively on a daily basis. I clearly remember PLN clients sharing their experiences of stigma and how they overcame all the challenges. These individuals later volunteered to be interviewed for this study. Their stories suggest that in

[1] Positive Living North is an AIDS Service Organization (ASO) situated in Prince George that provides support, awareness education, and prevention services to people living with, affected by, and at-risk for HIV/AIDS/HCV (Positive Living North, 2011).

spite of their struggles with stigma, fear, shame and discrimination, they have chosen to fight back and live positively.

As a researcher, I am interested in highlighting the individuals' lived experiences. While I may never walk the proverbial mile and half in these individuals' shoes, my life and volunteer experiences sparked my interest in the stories of those impacted by HIV. Their stories have been an inspiration and motivation for my own life. In this study, it is my desire to share their stories from their own perspective. These stories show resiliency that service providers, advocates and clinicians could support as part of their response to the epidemic of stigma.

Outline for the Thesis

In this chapter, I have given an overview of the HIV epidemic, and of the concepts of stigma and resilience. In addition, the relevance of using a resilience approach in understanding the lived experiences of these participants is included in this chapter. The information in this chapter also presented the purpose and significance of such a research. Likewise, I have located myself as researcher and examined my motivations, personal and professional reasons for conducting this study. The details outlined in this chapter are foundation to the other chapters presented in my thesis. Chapter 2 is the literature review which highlights the definition of stigma, and two theoretical frameworks that are used to guide this study: Goffman's theory of stigma and resilience theory. Additionally, the literature review reports the impacts of stigma and the link between HIV and stigma. This chapter also explored the concepts of resilience. In Chapter 3, the research paradigm of hermeneutics phenomenology is presented, along with data collections methods. Included in this chapter is the method of analysis and limitations. The results of the study are presented in chapter 4 and this will highlight the essence of the phenomenon stigma and resilience. Chapter 5 includes a discussion of the findings in relation to

the literature and the frameworks used to inform this study. Additionally, this chapter will summarize the findings on the impacts of stigma and resilience, and highlight the limitations of the study. The findings also put forward recommendations for future research. The finals part of this chapter is the conclusion and the implication for practice.

Chapter 2: Literature Review

In order to understand stigma, two theoretical frameworks will be presented. They will help to support the exploration of stigma experiences, responses to stigma, and resilience of individuals living with HIV/AIDS. The frameworks are Goffman's theory of stigma, and resilience theory. Issues relating to stigmatization and resilience will also be discussed. The following term, stigma, HIV/AIDS, and resilience will be discussed based on the literature.

Stigma

One of the most notable features of the literature concerning stigma is the variability in the definition of the concept (Link & Phelan, 2003). In many circumstances, researchers provide no explicit definition. They seem to refer to the dictionary definition for stigma, "a mark of disgrace associated with a particular circumstance, quality, or person" (Oxford University Press, 2013). The term stigma is derived from the Ancient Greek term. It refers to a tattoo mark which is branded on the skin of the individual, to reflect some incriminating action. This physical mark publicly identified the individual as blemished and morally degenerate, and as someone to be avoided (Crawford, 1996).

More academic definitions addresses stigma as a social construction, meaning that it is culturally determined, and is understood differently in different contexts. According to Fife and Wright (2000), "stigma is not a singular concept expressed and experienced in a common way, rather it is a complex phenomenon expressed both subtly and overtly" (p. 51). The UNAIDS (2003) define stigma "as process of devaluation of people either living with or associated with HIV and AIDS. Link and Phelan (2001) defined stigma in terms of the presence and convergence of four interrelated components. Firstly, people distinguish and label human differences. Secondly, members of the dominant cultural group link labelled groups to certain

undesirable attributes. Thirdly, negatively labeled groups are placed in distinct and separate categories from the non-stigmatized. Fourthly, as a result of the first three components, individuals who are considered part of a labelled group experience status loss.

Goffmans' Theory of Stigma

Erwin Goffman, a sociologist and a well-regarded researcher on the concept of stigma, is one of the seminal authors who highlighted stigma in a sociocultural context. Widely considered as the father of social stigma research, Ervin Goffman's conceptualization of stigma is the foundation for most stigma and stereotype theory and is considered to be the first sociological theory of stigma. Goffman describes stigma as an "attribute that is deeply discrediting" and as one that reduces the affected person "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Goffman refers to this as a spoiled identity (Goffman, 1963). This means that regardless of how a stigmatized person presents themselves, other people will only see the stigmatizing characteristics of the individual, rather than the person themselves. This inability to present a 'true' or 'authentic' self has major personal and social impacts. As such stigma is a process of social construction where specific people are assigned membership to a social group that is both discounted and discredited as a result, they are being reduced in the minds of others as being whole or acceptable.

Goffman's theory has been used to examine stigma experienced by the marginalized communities for the past half-century, and cited extensively in qualitative and quantitative studies (Castro & Farmer, 2005; Herek & Capatino, 1997). It has also been cited in literature that is specific to the stigma experiences of individuals with HIV/AIDS (Castro & Farmer, 2005; Herek & Capatino, 1997). Goffman's theory of stigma provides a theoretical framework that can afford the reader with an initial understanding of the stigma experiences of individuals living

with HIV/AIDS. In light of this, Goffman's framework will be used to guide this research and understand the concept of stigma.

Goffman's theory states that society consists of two kinds of people: the normal and the stigmatized (1963, p. 130). According to Goffman, normal people are those who do not have an underlying cause or factor that is stigmatized (p. 130). Goffman categorizes the stigmatized (those who experience stigma), into two groups: 'the discredited and the discreditable' (p. 41). Individuals, whose stigma conditions are apparent, are called discredited individuals. As it relates to this research, these may be individuals who have AIDS-related complications such as Kaposi sarcoma.[2] On the other hand, the stigmatizing conditions of the discreditable individuals are not apparent. An example of this is an asymptomatic HIV positive person. These individuals often have to choose whether they wish to disclose their condition and if they choose to do so, to whom and where to make this disclosure. Based on Goffman's theory the stigmatized can find support from a variety of social groups, for example from those sharing the same stigma thus making the discredited and discreditable feeling "normal".

Stigma can be expressed in three forms: physical stigma, stigma of character traits, and stigma of group identity. Stigma of character traits are "blemishes of individual character perceived as weak will, domineering, or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder,

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[2] Kaposi's sarcoma is a cancer that causes lesions or patches of abnormal tissue to grow under the skin, in the lining of the mouth, nose, and throat or in other organs. The patches are usually red or purple and are made of cancer cells and blood cells. Individuals infected with HIV virus that is untreated or poorly managed for a long period of time, will experience weakened immune system, and due to body being immunocompromised individual are more likely to develop infection /medical complications such as Kaposi sarcoma. Kaposi sarcoma is considered AIDS defining illness, in that when symptoms are present the individual is classified has having AIDS (National Cancer Institute, 2014).

imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior "(p. 10). Physical stigma refers to physical deformities [visible disfigurements/disabilities] of the body that are readily seen by others (p. 4). In this situation, there is a deficit between the expected norm of a perfect physical condition and the actual physical condition such as changes in physical appearance and function. Finally, stigma of group identity is a stigma that comes from being of a particular race, nation and religion. These stigmas are socially constructed, can shift over time (such as the stigma associated with race) and can be transmitted through lineages and impact all members of a family.

Goffman's theory states that individuals who are stigmatized responds to stigma in various ways such as controlling the social information they present to the world, and by disassociating themselves from the biographical others who may be the cause of stigmatization (p. 65). Thus, by removing themselves from the context, individuals can formulate a new social identity (p 67). Goffman describes a lack of disclosure as "passing" (p. 73). In this scenario, an individual pretends to be a member of the normal group but secretly belongs to a stigmatized group. If an individual chooses not to disclose his or her stigmatizing condition, he or she may have to carry out passing behavior. Individuals classified as 'passers" draws on several information control strategies to conceal stigmatizing symbols, such as a change in identity to cover stigma, and avoidance of questions. This is only possible if the source of stigma is invisible.

Although Goffman's theory is widely used within stigma research, his theory has also been criticized in research literatures. According to Fine & Asch (1998), Goffman assigns a helpless role to the person facing stigma and does not acknowledge the fact that stigmatized individuals may make valuable contributions to their society. Also, Das (2001) argued that most

of the conceptions of stigma are constructed on an individualistic terms focusing on the perceptions and not providing adequate account of the problems individuals encounter. Parker and Aggleton (2003) have critiqued Goffman's conception of stigma as being too "static" (p. 14). According to the authors, stigma, particularly stigma associated with HIV/AIDS, is a phenomenon which changes according to the stage of HIV/AIDS disease and intersecting factors such as gender, sexual orientation, and race (Parker & Aggleton, 2003). Additionally, Sayce (1998) and Jewkes (2006) highlighted that Goffman's notion of stigma is too narrow and individual based and therefore not suitable for designing stigma intervention approaches. In spite of the various critiques of Goffman's model on stigma, its original framework is still highly respected and most used amongst researchers. His representation of the stigma model is considered valid within the academic field. Based on these tenets, this model is being used as the foundation of my research.

Resilience

Fundamentally, resilience is a general concept related to positive adaptation in the face of significant challenges. As stated, resilience is conceived as a dynamic process involving complex interplay of risk and protective factors (Woodgate, 1999). There are numerous conceptualizations of resilience from many different disciplines, all conveying their own nuances. According to the Merriam Webster Dictionary (2011), resilience is an ability to recover from or adjust easily to misfortune or change. Looking at other conceptualization of resilience, psychologist Werner (1995) noted three general usages: good developmental outcomes despite high risk status; sustained competence under stress; and recovery from trauma. Another, definition of resilience is positive adaptation despite adversity (Luthar, Cicchetti, & Becker, 2000). Luthar et al. (2000) have called resilience a construct with two distinct dimensions:

significant adversity and positive adaptation. From this perspective, resilience is never directly measured but is indirectly inferred from evidence of these dimensions. This idea of a two-part construct is accepted by other researchers (Masten, 2001; Yates et al., 2004). According to VanBreda (2001), resilience theory addresses the strengths that people demonstrate to enable them to rise above adversity. Therefore resilience means the skills, abilities, knowledge, and insight that accumulate over time as people struggle to surmount adversity and meet challenges (VanBreda, 2001).

Siebert defines resilience as the ability to bounce back from stress and adversity. Siebert further elaborated that:

> resiliency refers to the ability to cope with high levels of ongoing disruptive change, sustain good health, and energy when under constant pressure, bounce back easily from setbacks, overcome adversities, change to a new way of working and living when the old way is no longer possible and do all these things without acting in a dysfunctional or harmful ways (2005, p. 5).

Siebert characterizes the resilient as people who are "flexible, adapt to new circumstances quickly and thrive in constant change. Most importantly "they expect to bounce back and feel confident" (2005, p. 2). Looking at the context of my research which is focusing on stigmatized individuals living with HIV, this definition is suited to be used as the theoretical framework to guide my understanding of this complex concept.

Looking at the various definitions of resilience the common themes that emerge include personal growth and strengths; cultivating strengths, change and disruption (Coutu 2003; Flach, 2004; Siebert, 2005). The great surprise of resilience is the normality of the phenomena: Masten

quote, "resilience does not come from rare and special qualities but from ordinary everyday magic of ordinary, normative human resources in the minds, brains, and bodies of children, in their families and relationships in there and in their communities (2001, p. 227).

Resilience is an inferential and circumstantial construct that requires two major kinds of judgments (Masten, 1999; Masten & Coatsworth, 1998). The first judgment addresses the threat side of the inference: individuals are not considered resilient if there has never been a significant danger to their development; there must be existing or previous threats that could potentially disrupt normative development (Masten, 1999; Masten & Coatsworth, 1998). The second judgments is whether the quality of adaptation or developmental outcome is assessed or evaluated as good or satisfactory (Masten et al., 1999; Masten & Coatsworth, 1998). There is little debate about whether such criteria exist, but much controversy remains about who should define resilience by what standards (Luthar, Cicchetti & Becker, 2000; Masten, 1999).

Resiliency is not established by a single trait but results from multiple triumphs over several life experiences. These experiences are considered life changing events. Resilient individuals learn to value their life's disruptions and sustain normal personal development (Garmezy, 1993; Rutter, 1985). Blum (1998) claimed that individuals experienced feelings of excitement when they overcame tremendous odds. The author further stated this excitement came from knowing they had been through a difficult period, but they found an inner strength that propelled them beyond what they thought they could endure. According to Higgins "resilience emphasizes that individuals do more than merely get through" (1994, p. 1); they develop a stronger faith and deeper satisfaction in themselves.

Resilience Process

The process of resilience is complex and it involves interaction between adversity and an individual's internal and external protective factors as well developed competencies that allow one to overcome adversity (Hunter & Chandler, 1999). Protective factors, such as family and community supports, act as buffers against negative outcomes and help promote adaptation (Wagnild, 2003). Resilience is understood, therefore, not only as a characteristic of the individual, as an innate ability, inherited by some privileged, but also as part of the existing dynamic interaction between individual characteristics and their social context (Rutter, 1987). Resilience is a comprehensive process that involves understanding personality traits, external factor such as family, friends, support group as well as outcomes such as increased self-esteem or social competence (Woodgate, 1999). Recent research that looks at the resilience process suggests this process in adults involves five dimensions: (1) connectedness to social environment; (2) connectedness to family; (3) connectedness to the physical environment; (4) connectedness to a sense of inner wisdom internal characteristics; and (5) a personal psychology with a supportive mindset and a way of living that supports the individual's values (Windle, 2011; Woodgate, 1999; McAllister & McKinnon, 2009).

Many studies have demonstrated the importance and the contribution of various factors in the process of resilience. A study of 195 children affected by HIV in rural China examining the relationship between social support, resilience, hopelessness and depression reported that children affected by HIV showed lower level of hopelessness and increased resilience if they had social support. The findings from the this study showed that resilient children were more likely to focus on positive emotions in time of adversity and tend to use positive coping strategies to manage negative emotional experiences (Masten, 2001; Kit Han Mo, Tak Fai Lau, Yu and Gu

2014). In addition, resilience intervention approach was positively correlated to self-esteem, where individuals were more capable of handling stressful events and experience personal growth during stressful situations (Dolbier, Jaggars & Steinhardt, 2010). Similar findings were presented by Fang et al., (2015), where participants with greater resilience, experienced better physical, emotional and functional wellbeing, indicating that resilience may diminish the negative effects of stress in this group.

Resilient characteristics. The five core characteristics Wagnild (2010) used to define resilience are purpose, perseverance, equanimity, self-reliance and self-contentment (also referred to as existential aloneness. These five core characteristics are known as one's resilience core, considered to be the most important part of one's inner being (Wagnild, 2010). According to Wagnild (2010) purpose is considered the foundation of one's resilience core and is associated with a meaningful life. Without purpose in one's life, there is lack of ambition in which progress can be derailed. Building on the foundation of the resilience core, the next characteristic is perseverance. Wagnild (2010) defines perseverance as the ability to push forward regardless of current situations or circumstances. The third characteristic of one's resilience core is equanimity which Wagnild defines as balance and harmony regardless of good or bad circumstances which creates equanimity (Wagnild, 2010, p. 3). Equanimity is a trait that describes individuals who are optimistic and open to possibilities of whatever life brings regardless of their current situations. Wagnild (2010) stated that "equanimity also manifests itself in humor (p. 3), thus when faced with adversity resilient individuals can laugh at their self and circumstances. The fourth characteristic trait that forms a part of the resiliency core is self-reliance. Self-reliant individuals learn from their experiences of adversity and challenges and in the process develop problem learning skills from these experiences. The more the individual

encounter challenges, their skills of self-reliance are refined, and strengthen and self-confidence strengthened (Wagnild, 2010). Finally, the last resilient core characteristics trait that was discussed by Wagnild, is existential aloneness. This characteristic trait addresses the fact that resilient individuals learn to live with themselves (p. 4) and thus become comfortable with whom they are and what they have become. Therefore, one who possesses existential aloneness is satisfied and content with his or her life regardless of past failures and disappointments.

Selected researchers have critiqued the concept of resilience. An issue which Killian (2005) presented is that there is disagreement about the timing or chronology of resilience. Does resilience exist before the adversity; does it come into being at the time of adversity; is it developed in response to adversity; or does it begin to emerge as part of a process of recovery understood as a process of adaptation when challenged by an adversity (Killian, 2005). It was noted when researching the term that much of the empirical research looking at the concept of resilience has been dominated by investigating children and the majority of the research is quantitative in nature using a resilience scale to objectively identify resilient individuals. Arriving at a clear understanding of resilience is difficult due to the complex nature of the phenomenon, and there are numerous issues related to defining the construct of this term. According to Woodgate, resilience may be viewed in a multitude of ways, in that it may be viewed as a trait, as an outcome or a process that is affected by protective and vulnerability factors (Woodgate, 1999). Resilience is a complex dynamic process that evolves over time. Thus, the manner in which the resilience process unfolds is shaped not only by the qualities of and characteristics of the person considered to be at risk but also by external factors and the nature of the risk variable or variables (Glantz & Johnson, 1999; Ungar 2004). For the scope of this research resilience is viewed as a process of adaptation where internal traits such as inner

strength and external factors such family and friends and AIDS Service Organization (ASO) contributes to the process of resiliency. PLWHA have various journeys, different experiences and/or social contexts. As such, resilience developing from stigma is not a linear process and has different meanings for each individual. Therefore, the research highlights the process of resiliency from PLWHA Lived experiences and the factors contributing to the process.

HIV/AIDS

In North America, the total number of PLWHA increased from an estimated 1.1 million in 2001 to 1.4 million in 2011 and about 51,000 people were newly infected with HIV in 2011 (UNAIDS, 2012). While HIV was initially limited to certain geographical locations, HIV has exploded and has become one of the worst epidemics worldwide (UNAIDS, 2012). In 1981 HIV was first detected when the Centers for Disease Control and Prevention (CDC) reported an unusual number of Pneumocystis carinii pneumonia cases in otherwise healthy gay males in the United States of America (Fenton & Valdiserri, 2006). Due to the mystery of the disease in the initial stages, speculations existed about the nature and origins of the virus. The virus was positively identified in 1983 and by 1996 the mechanism by which HIV infected the human immune system and caused AIDS was moderately understood, which later helped in identifying variations in the virus world-wide (Plantier et al., 2009). HIV infection is caused by two main types of virus, HIV-1 and HIV-2, and globally, HIV1- accounts for the majority of HIV infections (De Cock, 1993). HIV-2 is mostly confined to West African regions with a small number of cases in Europe and other parts of the world (De Cock, 1993).

Technological development and advance studies have led to the understanding of the mechanism of transmission compared to the 1980's when the disease was first identified and limited knowledge existed. In terms of transmission, after exposure to the HIV virus, the viral

RNA is not detectable in the circulatory system of the human body until 10 days, referred to as the window period, after which the virus increases exponentially and peaks around 21-28 days (Haase, 2011). Immediately following the peak period, patients develop symptoms of acute retroviral syndrome (Haase, 2011). Over a period of time, HIV weakens and eventually destroys the function of the immune system, by depleting key triggers to immune responses resulting in the inability of the immune system to defend against infection. A healthy uninfected individual has 800 to 1, 200 CD4-T lymphocytes (also called T -helper cells, which plays a vital role in the immune function and response) per cubic millimeter of blood (mm^3) (Kamya, 2004). However, when the immune system deteriorates to dangerously low immune levels the observed CD4 T lymphocytes are less than 200 per cubic millimeter of blood (mm^3) due to the fact that the HIV virus disables and kills T-helpers cells and reduces the ability of individuals to produce new T-helpers cells (Kamya, 2004; McCune, 2001). At this stage, the individual becomes susceptible to opportunistic infections such as Pneumocystis carinii, certain types of lymphomas and Kaposi's sarcoma: this is considered to be the end stage of HIV disease, called AIDS (NIAID, 2009).

HIV in Canada

At the end of 2005, an estimated 58,000 people in Canada were living with HIV infection (including AIDS) which represented an increase of about 16 % from the 2002 estimate of 50,000 (Boulos, 2005). Three years later, over 65,000 persons were living with HIV, and the number of new infections increased by 14 % to around 8,000 persons (Canadian AIDS Treatment Information Exchange [CATIE], 2010). The number of new cases has remained stable since 2008, estimated at 3,300. Despite this the number of HIV cases continues to rise due to new treatments, improved access and longer survival and thus HIV/AIDS still remains a serious concern for Canada (Public Health Agency of Canada (PHAC), 2012).

Broken down by HIV transmission rate, an estimated 46.7 % of HIV infections were attributed to men who had sex with men (MSM) which continues to account for the majority of HIV infections in Canada (Public Health Agency of Canada [PHAC], 2012). Those who acquired their infection through heterosexual contact and were not from an HIV endemic region comprised the next largest group (17.6 %), followed by those who acquired their infection through injection drug use (IDU) (16.9 %) and those exposed through heterosexual contact and were also from an HIV endemic region (14.9%) (Public Health Agency of Canada [PHAC], 2012).

In British Columbia, while Aboriginal people make up less than 4 % of the province's population, this group accounted for almost 15 % of the HIV infections reported between 1995 and 2001 (Public Health Agency, 2012). However, Aboriginal people remain disproportionately affected by wider societal issues such as poverty, substance abuse, and limited health-care access. It is therefore unsurprising that the overall HIV infection rate amongst Aboriginal people is estimated to be almost three times higher than for non-Aboriginals (Public Health Agency of Canada (PHAC), 2012). The most common route of infection amongst Canadians living within northern British Columbia, particularly Prince George, is injection drug users (IDU), exacerbated through IDU during imprisonment (Haag et al., 2007).

Northern British Columbia. Although accounting for relatively small percentage of the population of people living in BC, northern British Columbia spreads out over a large geographical area. Prince George, the largest city located in northern British Columbia (BC) with a population of 84,232 (Statistics Canada, 2012), is located at the crossroads of highway 16 and 97.

In northern BC, a high prevalence of Hepatitis C (HCV) is an indication of the HIV epidemic, owing to risk factors common to both diseases such as needle borrowing and related to the difficulty in accessing uncontaminated needles (Northern Health, 2007). The rate of HCV and HIV in northern communities is above the rate of BC: for example, in 2009 the rate of HIV newly identified cases was 9.5 per 100,000 (27 individuals) compare to 7.5 per 100,000 in the rest of BC. In terms of the breakdown in routes of transmission, 56 % identified using intravenous drugs, 15 % identified as heterosexual with no other identifiable risk, 11 % identified as heterosexual with other risk factors (Northern Health, 2010). There are a number of reasons to explain the increasing incidence rate of HIV in northern BC. Firstly, geographic and demographic features converge to create a shortage of human resources, infrastructure, and supplies for all health issues, including HIV/AIDS (Northern Health, 2007). Secondly, the Northern Health Authority covers over two-thirds of the land mass of the province of British Columbia (Northern Health, 2007). Within this large territory there are just eight communities with populations over 10,000 people, and more than 60 smaller, predominantly First Nations communities, many of which are very remote.

HIV and Stigma

HIV/AIDS-related stigma (or, more simply, AIDS stigma) is used to refer to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, as well as the individuals, groups, and communities with which they are associated (Herek, 1990; Herek & Glunt, 1988). According to UNAIDS, HIV/AIDS-related stigma and discrimination are defined as "a process of devaluation of people either living with or associated with HIV and AIDS, and discrimination follows stigma and thus the unfair and unjust treatment of an individual based on his or her real or perceived HIV status" (2003, p. 9). Goffman's three-

dimensional construct of stigma reflects that of HIV/AIDS: HIV/AIDS can result in physical manifestations, particularly in latter stages; it can also be associated with socially marginalizing personal traits such as homosexuality and drug-use; and lastly, it is a communicable disease that can be transmitted sexually. All of these factors combined contribute to HIV being a highly stigmatized condition. According Hasan et al., (2012) PLWHA experience enacted and felt stigma. Felt stigma also called internal stigma or self- stigmatization refers to shame, blame and the expectation that persons will discriminate against PLWHA (Scambler, 1998). In addition, Brown, Macintyre and Trujillo (2003), state that felt or internal stigma refers to real or imagined fear of societal attitudes and the potential for persons to discriminate due an undesirable attribute, such as HIV, or association with a particular group or behavior. On the other hand, enacted stigma or discrimination refers to the experience of PWLHA being treated differently, or persons losing their job because of their diagnosis (Scambler, 1998). Both felt and enacted stigma influence the way in which people living with HIV view themselves and cope with their HIV status.

According to Lee, Kochman & Sikkema (2002), HIV-related stigma is "heightened as it is layered upon other stigmas associated with race, gender, homosexuality, drug use, and promiscuity (p. 310). De Bruyn (1998) has identified five factors contributing to the high level of stigmatization:

1. The fact that HIV/AIDS is a life-threatening disease;
2. The fact that people are afraid of contracting HIV;
3. The disease's association with behaviors (such as sex between men and injecting drug use) that are already stigmatized in many societies;

4. The fact that people living with HIV/AIDS are often thought of as being responsible for having contracted the disease; and
5. Religious or moral beliefs that lead some people to conclude that having HIV/AIDS is the result of a moral fault (such as promiscuity or "deviant" sex) that deserves punishment.

According to Gilmore and Somerville the language and the metaphors used to depict HIV/AIDS include:

> AIDS as death- depicted by images of the Grim Reaper; AIDS as punishment for 'immoral behaviour'; AIDS as crime, often represented in the division of 'innocent' and 'guilty' parties; AIDS as war, in which the virus and sometimes people with HIV are seen as needing to be fought against; AIDS as otherness, in which polarities between sick and well, infected and uninfected are developed; and AIDS as horror, in which those infected are demonized and feared (1994, p. 4).

Overall, the negative depiction of people living with HIV/AIDS – reinforced by the language and metaphors used to talk and think about the disease – has reconfirmed fear, avoidance and the isolation of affected individuals and, in some cases, their friends and families. In a highly stigmatizing environment, people may withdraw from society as a means of self-preservation. Through these metaphors, individuals with HIV, including those associated with people with the disease are subjected to responses which scapegoat, stigmatized and discriminate them (Gilmore & Somerville, 1994).

The degree of stigmatization associated with HIV reportedly differs with the prevalence of the infection. In areas like Canada with low prevalence of infection where few communities

or families are affected, the illness tends to be highly stigmatized, while in high prevalence areas the disease may become normalized which may reduce stigma (MacIntosh, 2007). Although AIDS stigma is universal, it takes different forms in different countries, and its specific targets vary considerably and are shaped in each society by multiple factors including local epidemiology of HIV and preexisting prejudices within the culture (Herek, 1999). Unlike other infectious diseases, HIV/AIDS has been accompanied by a threat of death and disfigurement which has added to the fears and fantasies surrounding the epidemic. This has resulted in characterizations of AIDS as a disfiguring and frightening disease, with little hope of recovery or cure, and which threatens to devastate communities and societies. HIV/AIDS is not the only disease that is stigmatized (tuberculosis, mental illness, cancer for examples). What distinguishes HIV/AIDS from many illness and diseases are the many dimensions of HIV/AIDS related stigma.

Research has consistently shown that HIV-infected individuals living in low HIV prevalence areas continue to experience high level stigmatization and discrimination (MacIntosh, 2007). In a survey conducted amongst Canadians in 2011, although respondents were more knowledgeable about HIV/AIDS in comparison to the period of 2006 still 16% of survey respondents said that they "feel afraid" of people living with HIV/ AIDS; 18% said that they would be somewhat or very uncomfortable working in an office with someone who developed HIV/AIDS (Interagency Coalition on AIDS and Development, 2012). In addition, 35% of Canadians said they would be somewhat or very uncomfortable if their child was attending a school where one of the students was known to have HIV/AIDS; 54% would be somewhat or very uncomfortable with a close friend or family member dating someone with HIV/AIDS; and

23% expressed discomfort shopping at a small neighborhood grocery store, owned by someone with HIV/AIDS (Interagency Coalition on AIDS and Development, 2012).

In another study conducted, HIV discrimination was common among participants, with nearly a sixth of the sample of 366 females interviewed self-reporting HIV discrimination in one or more domains including their worksite, neighborhood and medical care. Specifically, 6.2% (20) had to relocate, 5.3% (17) reported losing a job, and 4.4% (14) were denied medical care as a result of being HIV positive (Wingood et al., 2007). However, much of the published quantitative research measuring stigma suggests that while support for extreme measures against people with HIV/AIDS has fallen to very low levels, the American public increasingly blames people living with HIV/AIDS for their illness (Stein, 2003). Similar research findings have also been presented by Sweendeman, Rotheram-Borus, Comulada, Weiss & Ramos (2006).

Impacts of stigma. The fear of the stigma associated with HIV/AIDS has been shown to reduce the likelihood that individuals will get tested for the virus and has been shown to decrease adherence with prevention programs, care regimens, which have a deleterious health impact (Chesney & Smith, 1999; Herek et al., 2002). Stigma not only makes it more difficult for people coming to terms with having HIV and manages their illness on a personal level, but it also interferes with attempts to fight the HIV/AIDS epidemic as a whole. Stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, and it can make individuals reluctant to access HIV testing, treatment and care (AVERT, 2012).

According to Omangi (1997), stigma generally affects individuals: firstly, stigma may cause deep personal pain to the infected and affected, and individuals may feel lonely and rejected. As such they may respond with denial, guilt, shame, anger and blame. Second, discrimination and stigmatization hamper efforts to respond to the needs of those infected and

affected. Thus, it is very difficult to reach many infected people with the necessary support and services, because they keep their serostatus a secret. Third, stigmatization and discrimination hinder open discussion about HIV/AIDS, creating an environment which only facilitates the rapid underground spread of HIV and thus prevention becomes troublesome (Omangi, 1997).

From a public health perspective, HIV/AIDS related stigma also fuels new HIV infections because it may deter people from getting tested, make individuals less likely to acknowledge their risk of infection and discourage those who are HIV positive from discussing their HIV status with their sexual partners and others (HRSA, 2003). The epidemic of stigmatization has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate prevention behaviors, including use of family planning services (Ogden & Nyblade, 2005, p. 33). Stigmatization causes a barrier to public action and on a personal level can reduce an individual's willingness to practice prevention, disclose his or her HIV status to others, access HIV testing, begin and adhere to treatment, and ask for (or give) care and support.

The WHO cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose their HIV status or to take antiretroviral drugs (World Health Organization, 2011). The disclosure of HIV infection is a necessary first step in accessing treatment and support as well as taking measures to prevent the transmission of the virus to others (Sowell & Phillips, 2010). Disclosure of HIV status is a difficult emotional task creating opportunities for both support and rejection. It raises issues of privacy, vulnerability, identification with a stigmatized role, and feelings of imposition on others (Yoshioka & Schustack, 2001). However, fear of negative outcomes was nonetheless the barrier to HIV status

disclosure most often mentioned by women in previous studies (Medley, Garcia-Moreno, McGill, & Maman, 2004). Similarly, fear of discrimination, victimization, accusation of infidelity, and of confidants spreading the news about their serostatus, was the most significant reasons associated with non-disclosure of HIV-serostatus reported by respondents (Akani & Erhabor, 2006).

According to Siegel, Lune, and Meyer (1998), individuals facing stigma associated with HIV/AIDS can respond in a number of ways. Some individuals may actively fight the stigma and make changes to include people who are supportive and remove those who actively stigmatize them. Other individuals, may try to hide their stigmatizing condition or pass it off as a condition less stigmatizing. This drives the HIV epidemic underground causing individuals who have contracted HIV into hiding with fears of accessing medical services, support and non-disclosure (Skinner & Mfecane, 2004). Additionally it can delay entry into treatment and adoption of healthy lifestyle. These factors all contribute to the expansion of the epidemic (as a reluctance to determine HIV status or to discuss or practice safe sex means that people are more likely to infect others) and a higher number of AIDS-related deaths (AVERT, 2012). An unwillingness to take an HIV test means that more people are diagnosed late, when the virus has already progressed to AIDS, making treatment less effective and causing premature death.

In a study by Sayles, Wong, Kinsler, Martins, & Cunnigham (2009), approximately one-third of the two hundred and two (202) participants reported experiencing high levels of internalized HIV stigma. The research findings showed that respondents experiencing high levels of stigma had over four times the odds of reporting poor access to care and are associated with suboptimal Antiretroviral therapy (ART) adherence (Sayles, Wong, Kinsler, Martins, & Cunnigham, 2009). Similarly, other findings have documented that PLWHA may be unable or

unwilling to appropriately utilize the health care system. This is resulting from a fear of labeling thus delaying individuals from seeking out, and engaging with, appropriate health services (Chesney & Smith, 1999; Herek & Capitanio, 1997).

The role of stigma in reducing uptake of antiretroviral therapy (ART) is unclear (Roberts, 2005). Stigma emerged spontaneously as the second most frequently listed reason women do not begin ART in a qualitative study in Zambia (Murphy, Austin, & Greenwell, 2006). The evidence is much clearer that stigma and discrimination present barriers to good adherence to ART. Perceived stigma and internal stigma were inversely associated with adherence in the US, United Kingdom, Brazil, Botswana, and China (Roberts 2005; Calin et al. 2007; Melchior, Nemes, Alencar and Buchalla 2007; Kip et al., 2009). Rintamaki and colleagues found that people in the United States with high HIV stigma concerns were 3.3 times more likely to be non-adherent to their medication regimen than those with low concerns (as cited in Dlamnini, et al. 2009).

Similarly, stigma negatively impacts PLWHA as it is internalized into their self-perception and sense of identity that negatively affects interactions with the world. According to the research findings of Brouard & Wills (2006), HIV infected individuals reported feeling isolated, guilty, dirty and full of shame. These feelings were associated with feelings of victimization, which then became an integral part of identity, at times resulting in social withdrawal, aggressive, and rude behaviors to colleagues and friends (Brouard & Wills, 2006). Bezuidenhoudt et al. (n.d.) reported that infected, and in some cases, affected, people they studied experienced a decrease in self-esteem, becoming no longer confident in themselves or what they can achieve. General participation in the activities of life was therefore restricted by stigmatization (Sowell et al., 1997). Internalized stigma might influence the ways affected

individuals look at themselves and how they interact with each other's including health care providers (Lee, Kochman, & Sikkema, 2002).

Summary

In summary, Goffman's theory of stigma and resilience theory form the theoretical framework for this research. The concept of stigma was explored and the link between stigma and HIV/ AIDS, and the impacts of HIV/AIDS were presented. Based on the literature presented, little research has been conducted looking at resilience and stigma from the perspective of person living with HIV, and how they bounce back despite experiencing adversity. It was the aim of this research to address this deficiency, by exploring stigma experiences both positive and negative and the factors that contribute to the process of resilience.

Chapter 3: Methodology

In order to answer the research questions for this study, relevant research data are necessary. The process of data collection and analysis in this study is based on qualitative research methodology. In this chapter I discuss the qualitative research approach that guided this study. The chapter will provide an account of the research design and will describe the research methods and data collection performed. The purpose of this research was to explore and highlight the lived experience of people living with HIV-related stigma in Prince George, secondly, to understand the impacts of stigma, and thirdly, to identify the ways in which those living with HIV/AIDS respond to stigma.

This study was underpinned by a qualitative research paradigm because it focuses on the lived experiences of participants, those living with HIV/AIDS and their experience of stigma and resilience. A qualitative study is an inquiry process based on the construction of a complex but holistic picture formed with detailed views of participants, and conducted in a natural environment in order to help understand a social or human problem (Creswell, 2007). Using this paradigm, each participant's own interpretations of reality is valued. Also, by using the qualitative research paradigm the research documented the participants' views as it related to stigma and resilience. Qualitative research aims to provide an in-depth understanding of people's experiences, perspectives and/or histories in the context of their personal circumstances or settings. It is characterized by a concern with exploring phenomena from the perspective of those being studied and by using unstructured methods which are sensitive to the social context of the study (Patton, 2002, p. 40)

The underpinnings for this study are based in hermeneutics phenomenology. Phenomenology is used to emulate or give voice to a phenomenon under study. According to

Patton (2002), phenomenology explores the "meaning, structure, and essence of the lived experience" of a certain phenomenon, for a "person or a group of people" (p. 104). As a philosophical base, phenomenology helps the researcher find and describe the essence of an experience from the participant's perspective (Giorgi & Giorgi, 2003). The main task of this research methodology is to investigate phenomena, including the nature of human experience, and the way these phenomena appear "in their fullest breadth and depth" (Spiegelberg, 1984, p. 2); i.e., to describe the way things appear, or particular phenomena, as lived experience (Speziale & Carpenter, 2007). The purpose of phenomenology is therefore to describe the lived experience of people; and the documentation of that experience so that their true lives are described (Anderson, 1993). Lived experiences are those influenced internal and external forces but involve conscious life's events before both reflection and interpretation (Penner & McClement, 2008).

Phenomenological Framework

The two main phenomenological perspective are descriptive (Husserlain) and interpretative (Heideggerian) phenomenology (Lopez & Willis, 2004). The main focus of Husserlain phenomenology is the rigorous and unbiased study of phenomena as they appear in order to arrive at an essential understanding of human consciousness and experience (Dowling, 2007). Husserl believed that subjective information should be important to scientists seeking to understand human motivation because human actions are influenced by what they perceive to be real (Flood, 2010). Additionally, Husserl believed that researcher should hold their subjective perspectives and theoretical constructs in abeyance and facilitate the essence of the phenomena to emerge, which is done through a process called phenomenological reduction (Dowling, 2007; Laverty, 2003). This process requires the researcher shed all prior personal knowledge

(bracketing) and this is to prevent their biases and preconceptions from influencing the study and ensuring scientific rigor (LeVasseur, 2003). The descriptive method phenomenology inspired by Husserl requires the researcher to makes no interpretation rather the participants description are analyzed and dived into meaning laden statements and the meanings are essential to the construct being studied.

On the other hand, Heideggerian phenomenology researchers maintain that the participants' experiences can only be understood and interpreted by another "being-in-the-world" (Heidegger, 1962). That is, individuals create meaning through the experience of moving through space and across time (Heidegger, 1962). Hermeneutics goes beyond description of core concepts and essences to look for meanings embedded in common practices (Lopez & Willis, 2004) what people experience rather than what they consciously know. Heidegger used the term 'lifeworld' to express the idea that individuals' realities are invariably influenced by the world in which they live. In addition, Heideggerian framework focus on describing the meanings of the individual's 'dasein' and how these meanings influence the choices they make rather than seeking purely descriptive categories of the real, perceived world in the narratives of the participants (Lopez & Willis, 2004).

Despite common interest in lived experience, there are few differences between Husserl and Heidegger phenomenology in how research findings are generated and are used to enhance knowledge. Heidegger differs from Husserl in his views of how the lived experience is explored, and Heidegger advocates the utilisation of hermeneutics as a research method founded on the ontological view that lived experience is an interpretive process (Dowling 2007; Laverty 2003; Sloan & Bowe, 2014). In addition, Heidegger contends that individuals own background, beliefs and personal experiences are a legitimate part of the research process that should not be omitted,

but rather incorporated into both data generation and analysis and are valuable guides to enquiry (Laverty, 2003). Furthermore, Heidegger (1962) emphasised that it is impossible to rid the mind of the background of understandings that has led the researcher to consider a topic worthy of research in the first place thus personal knowledge is useful and necessary to hermeneutics research (Flood, 2010). My research work focused on Heidegger's (1962) approach which aims towards illuminating the details and seemingly trivial aspects within experiences in individuals' lives that may be taken for granted (Wilson & Hutchinson, 1991). In choosing Heidegger phenomenology, I acknowledge that my pre-understanding is not something I can step outside of or put aside, as it is understood as already being a part of my experiences and will contribute to the research process, and my understanding of the participants'' stories.

Hermeneutics phenomenology. The term hermeneutics is derived from the Greek messenger god Hermes, whose task it was to convey understanding of divine matters to the mortals (Rathswohl, 1991). The underlying idea of hermeneutics is to provide a way of understanding texts. However, contemporary hermeneutics has moved away from the hope of being able to produce a 'correct' understanding and is looking for an appropriate interpretation of texts. Hermeneutic phenomenology is concerned with the lived world or human experience as it is lived. The focus is toward illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding (Wilson & Hutchinson, 1991). It is a "research methodology aimed at producing rich textual descriptions of the experiences of selected phenomena in the life world of individuals that are able to connect with the experience of all of us collectively" (Smith, 1997, p. 80). Hermeneutics' primary objective is the direct investigation and description of phenomena

as experienced in life by using the practice of phenomenological reflection and writing to understand the forms of life (Van Der Zalm & Bergum, 2000, p. 212).

Lester (1999) noted that phenomenological research is a powerful understanding of the individual's subjective experience, and emphasized the importance of personal perspective and interpretation in gaining insights into peoples' motivations and actions. Hermeneutic research focuses on the essence of one's lived experience: it is interpretive and concentrated on historical meanings of experience, and their developmental and cumulative effects on individual and social levels. Persons living with HIV/AIDS-related stigma are experts in sharing their stories. Through this methodology, stigmatized individual living with HIV/AIDS are able to share their lived experience, especially in relation to how they perceive stigma and discrimination and their responses to this phenomenon. This methodology allowed me to carry out an in-depth and intimate examination of stigma and resilience as a lived phenomenon. The goal fits with the philosophy, strategies and intentions of hermeneutic phenomenology research paradigm. However the main focus of phenomenology is with pre-reflective experience and understanding the essence of a phenomenon. A key aspect of this study was exploring individuals' experience of living with HIV as it relate to stigma and documenting the ways in which they respond. Hermeneutic enables the exploration of participants' experiences of stigma and resilience, and adds rich dense description of the phenomenon being studied in a particular context.

Relationship Building and Cultural Safety

Relationship building is important for the type of study undertaken for this thesis. Linda Smith (1999) postulates that defining community research is as complex as defining community. Each of the participants is unique culturally and as such, must be recognized for how they identify health and wellbeing, health promotion, challenges, and successes. Kirkness &

Barnhardt (1991) guiding principles of the 4 R's Respect, Relevance, Reciprocity, and Responsibility must be acknowledged. For the purpose of this study, I am cognizant of the following process:

Respect – the researcher must be aware of the unique aspects and focus from each of the participants. I, as a researcher must hold high respect for the participants' lived experience and diverse backgrounds.

Cultural safety according to Ramsden (2002) develops the idea that to provide quality care for people from different ethnicities and cultures, health providers must provide that care within the cultural values and norms of the participants. She elaborates further by reminding everyone that cultural safety is well beyond cultural awareness and cultural sensitivity. It gives people the power to comment on care and to be involved in changes where their experiences have been negative. Cultural safety is a beginning step toward understanding that there is a difference therefore; I will be approaching the participants with the upmost respect.

Relevance – the researcher must look, learn, and listen, and to remain humble during storytelling. In addition, it is important for the research to be relevant to the participants. The focus of stigma came out of prior research work and attending positive prevention meeting with members of PLN. Listening to the stories of PLWHA, stigma and the impact of this phenomenon on the lives of PLWHA was a reoccurring theme. Also, talking with members of PLN about possible research ideas for my master's thesis the topic of stigma was suggested. In conducting this research, it was important that the research was relevant to the people by the people and for the people (Kenny & Fraser, 2012). Stigma and resilience is an issues that this thesis will address since it is a relevant element of PLWHA stories and capture their journey living with HIV.

Reciprocity – the researcher will need to gift back to the participants who have worked so diligently at sharing their stories. The gifting of words exchanged is one of the most powerful and memorable moments. The emphasis of this research is to make this a two-way process, in which there is give-and-take between researcher and participants (Kirkness & Barnhardt 1991). As such, a copy of the thesis will be a given as gift to PLN and used by the education department as a medium to share the stories of PLWHA in schools, organizations and the community.

Responsibility – as a researcher, it is most important to own behavior. Researchers are responsible for how they engage, observe, and obtain information. It is my responsibility to protect the participants in any case and to provide resources easily available to access. Also it is my responsibility as a researcher to integrate with the people, to create a level of trust in the sharing of their stories. As such, time was spent participating in activities of PLN engaging and learning more about the culture of the people and that the research was done according to the community's protocols.

Study context and site selection

This study was conducted in Prince George, British Columbia (BC). Prince George is a city located on the traditional territory of the Lheidli T'enneh with a population of approximately 70,000 situated at the confluence of the Fraser and Nechako Rivers (Statistics Canada, 2012). The site of the study was Positive Living North (PLN) and this organization was selected because of my involvement as a volunteer/research assistant and developing close working relationship with members and staff. PLN was launched on August 12, 1992 as the Prince George AIDS Society, and is a community based organization which provides education,

prevention, and HIV/AIDS support service in the Prince George region (Positive Living North, 2011).

Participants. The participants in this study were PLWHA, living in Prince George and who are affiliated with the non-profit organization, PLN. Seven participants were interviewed with ages ranging from 27-52years. In qualitative research, Creswell (2007) advises that the goal is to select a few individuals and conduct in depth interviews in order to explore the full meaning of the phenomenon. In this study, the participants were interviewed for approximately an hour on issues and variables relevant to the research topic, reflecting on their experiences and knowledge of stigma and resilience.

Convenience and network sampling (Brink & Wood, 1994) was used to recruit individuals living in Prince George. Participants were recruited from PLN. The Education Director and Support Services Manager provided members and non-members associated with the organization with information about the project. Interested participants were provided with a project information flyer (see Appendix A) with student researcher and supervisor's contact details.

Data Collection

Interview procedure.

Informed consent. Before the start of each interview participants were informed of the interview procedure. Participants were informed that the interviews would be confidential and that their names will not be used in the transcription and/or in the thesis, instead participants were assigned a number (see Appendix B & C) in order to protect confidentiality and anonymity. Also, verbal explanation of the consent form detailing confidentiality, and the nature of the

research was explained to each participant (see Appendix B & C). After which, if participants agreed to continue with the study they were asked to signed the consent forms. Additionally, permission was requested from each participant before the start of each interview to tape record the interview.

Data collection. The method of data collection used was in-depth interviews. The aim of using interview was to gain information on the perspectives, understandings and meanings constructed by people regarding the events of their lives (Grbich, 1999). Due to my limited experience in qualitative research, I conducted mock interviews with an experienced graduate researcher to gain insights on interview techniques. The interviews were semi-structured and open-ended. Participants were also given a short demographic questionnaire that asks the following information: age, race or ethnicity, place of birth, and years living in the Prince George (see Appendix D).

Each interview began with warm-up questions in order to help participants slowly engage in the conversation and to "open up". A list of open ended interview questions (see Appendix E) were used, follow up questions that help to clarify responses or probe for a more in-depth response were also used in order to capture the essence of the phenomenon being studied. Open-ended questions (questions that begin with "what and how") were asked in order to access participants subjective experiences and perceptions. The recorded interviews lasted from 45 to 90 minutes. The use of a digital recorder allowed me to concentrate on listening and responding to the interviewee and eliminated the possibility of being distracted by writing. Further, the recording of the interview ensured that the entire verbal encounter was captured, and provided accurate and complete data for analysis. All interviews were transcribed and stored electronically. Recording of the interview allowed replay if needed, in order to obtain missed

information or clarification. This increased the accuracy and validity of the content of the transcribed interview. After the interview participants were given an honorarium of $20 Gift card (for a local grocery store or a popular coffee shop, as chosen by the participant).

Emotional safety. This research focused on a topic, HIV and stigma, that is considered sensitive in nature and there may be implications for many people who are involved. As such it was important to maintain psychological safety of all the participants involved in the research process. Participants were asked to tell their stories about living with HIV, and they were sharing personal, often intimate aspects of their lives. As such, it was important for participants to feel safe and secure. One method of providing emotional support was conducting interviews in a calming environment. Interviews were conducted at PLN in the members' room and by doing so this provided a calming space, where participants would feel safe and comfortable to share their experiences.

In addition, given that individuals were talking about upsetting or emotionally charged experiences, at the end of the interview, all of the participants became somewhat emotional. Where necessary, I changed the course of the interview to ask questions that did not elicit such emotional response and checked in to make sure that participants wanted to continue with the interview. At the end each the interview, the participants were given a list of resources in the community, should they feel the need to utilize any services outside of PLN for support, including:

- UNBC Community Care Centre - 1310 3rd Avenue- (250-90-6457)
- Northern Aboriginal HIV/AIDS Task Force-987 4th Avenue – 9250-562-3591)
- Central Interior Native Health Society- 1110 4th Ave- (250-564-4422)

Another important component of emotional safety that is often overlooked is that of the researcher. As the researcher, it was important to ensure that a number of methods were carefully considered while conducting this research to deal with my psychological safety. I consciously focused on the positive things that were happening in my life, and also focused on the resiliency components of participants' stories where they shared accomplishments and victories. In addition, another mechanism for controlling my emotions involved acknowledging my feelings in my self- reflective journal. The journal-writing provided a sense of relief, and gave me an opportunity to share my feelings. Other precautions taken involved me limiting the number of interviews to one, or at most two per day. Also, after listening to interview tapes, I took a break or change of activities. On the third day of interviews, I was feeling overwhelmed, so I took a break from listening to the tapes and spent time with friends at the lake. In addition, after the interview process, I debriefed with the coordinators at PLN. The debrief included my reactions to the material and receiving advice on ways to deal with the various emotions I was experiencing (McCosker, Barnard & Gerber, 2001).

Analysis

Exploring the experience, impact of and response to stigma was central to this research. I also wanted to know how participants employed resilience when they respond to stigma. The data analysis was centered on the guiding framework of hermeneutic phenomenology, and followed the following steps.

Transcription. The process of analyzing the data occurred simultaneously with data collection. All transcripts were entered into the QSR NVivo data management program and data coding was conducted. The analysis used for this study was the qualitative technique of thematic

analysis, which incorporates the inductive approach (Braun & Clarke, 2006). Thematic analysis is a search for themes that emerge as being important to the description of the phenomenon (Daly, Kellehear, & Gilksman, 1997). Additionally, it is a form of pattern recognition within the data, where merging themes becomes the categories for analysis. The analytic process involve moving from description to interpretation, where the significance of the patterns and their meanings and implications were highlighted (Patton, 1990).

Description of phases. In my analysis the six phases of thematic analysis by Bran and Clarke (2006) was followed : a) familiarize yourself with the data; b) generate initial codes; c) search for themes; d) review themes; e) define and name themes; and f) produce the report.

1. I familiarized myself with the data by: listening to each recorded interview, reading each transcript at least twice, and transcribing all the interviews. This was done so that I could fully immerse myself in the data and have a better appreciation for the realities of participant's experiences with stigma and resilience.

2. After familiarizing myself with the data, I then started the process of coding. I went line by line to generate to initial codes. I generated codes using NVivo software, and I also did this process manually by highlighting the different codes with various colors of highlighter and writing notes on the transcript. I was most comfortable with the manual method and the process went faster since greater amount of time was spent learning QSR N VIVO software. However when I fully understood the software, it made the whole process of coding much easier. After generating the initial codes I realized that my codes

were too vague so I repeated the process and further refined my codes. I created a table with all my codes for each transcript and defined each code with an inclusion and exclusion criteria. This procedure was done for all the transcripts.

3. After refining my codes, I examined the various codes from all the transcripts and searched for possible themes. I searched for repeated codes, such as: loss of job, financial problems, drug abuse and then I created a table with potential themes from my defined codes.

4. During this stage of defining and reviewing themes I had to consult with my supervisors as this was becoming a hard process. With the assistance of my supervisor I used a mind-map to generate and visualize possible themes from the transcripts.

5. Further consultation with my supervisor I then realized there was some overlapping in themes. I then embark on the hard process of defining the themes and including inclusion and exclusion criteria. I defined and named themes according to the essence of what each theme was about and then I finalized them on a table. In the findings I quoted the participants' own words as much as possible in order to finish the phenomenon and thus tell their stories.

Limitations

Cross-race interviewing (Black researcher interviewing people of different race) can be seen as a limitation of the study. However, some researchers (Andersen, 1993; Rhodes, 1994;

Twine, 2000) claim that cross-race interviewing can provide an important perspective that may generate different but valuable information. Another limitation is that participants might see the researcher as an outsider, just another researcher who wants to gain information for their own benefit. While this interviewer effect may be seen as limitations to the validity of the research; I believe my rapport and own personal experiences volunteering at PLN and previous research with these participants assisted in obtaining information that might not have been gained by a researcher with a different social location.

Rigor

According to Collingridge & Grant (2008), validity refers to the extent which research measures what it purports to measure. Conducting a phenomenological research validity and trustworthiness is cultivated in the participant's stories, experiences, as they are self-interpretative. Since it is possible that questions or answers will be misunderstood due to difference in worldviews and experiences, steps were taken to ensure that this research was valid and trustworthy. At all stages of the research process I remained open, considered all ideas even those that were not supported in the literature as this was the participants' lived experience. Also, I listened closely to the data making sure to set aside previously held assumptions, and documented these in my journals (Walcott, 1990). Similarly, I recorded all information, initiated writing early, included all relevant data in the final thesis, sought feedback from participants after their interview was transcribed, to ensure that the information reported was accurate and complete (Walcott, 1990).

According to Guba (1981) trustworthiness in qualitative research can be assessed through four avenues: credibility, transferability, dependability and conformability. In terms of creditability, as a researcher there was prolonged engagement with participants as a means to

increase credibility. According to Guba (1981), the reason to practice prolonged engagement is to "overcome . . . distortions produced by the presence of researchers and to provide researchers the opportunity to test their own biases and perceptions, as well as those of their respondent" (p. 84). Concerning prolonged engagement I volunteered at PLN for over one year before the study, and all participants had interacted with me on previous occasions during members meeting, or other functions. My presence and prior working relationship facilitated ease during the interview process since participants were familiar with me, and trusted me. The use of strategies such as these allowed me to build trust with the participants and be able to disclose their experiences, which in turn contributed to the authenticity and rigor of the research.

Additionally, during the interview I made notes of body expressions, tone of voice and other response. As this is an important part of sharing their experiences. Member checking was also done to improve credibility. In terms of dependability I have kept an audit trail of not only my interview notes but of my research process.

The following rules were applied to ensure the information reported was accurate and complete:

Personal reflexivity. Using an interpretivist framework in understanding the phenomenon of stigma and resilience supports the ontological perspective in the existence of multiple realities that were constructed by the participants in this study through their interactions and experiences living with HIV/AIDS (Laverty, 2003). According to Guba (1981), it is of primary importance for the researcher to practice reflexivity. The hermeneutical approach includes the process of self-reflection, where the researcher's assumptions and biases are not set aside or bracketed, rather, they are acknowledged and become embedded in the research (Laverty, 2003). Reflexivity – a person's reflection upon or examination of a situation or

experience - can help in interpreting the meanings discovered, or add value to those types of interpretations (Laverty, 2003). I wrote in a self-reflective journal to record and increase my awareness of my personal biases as well as to record my cognitive and emotional reactions to participants' responses in the interviews. These journal entries informed the analysis and the discussion with regards to how my own reality was affecting or biasing my interpretation of the data.

Using the reflective journal as a tool, I found this process to be very powerful. For example, one participant expressed the idea that they were happy to have HIV, because the diagnosis had encouraged them to think about life. I was surprised at such a response, but I wrote in my journal "this is the person's experience, this person is the best judge of this statement". I took what the participants said in answer to their questions as truth and accepting the idea of multiple realities instead of a single reality (Creswell 2007).

Particularly as an emerging researcher, it was unrealistic for me to attempt to completely separate my research from my personal beliefs and values. In fact, it was often difficult for me to maintain my composure as participants shared their stories with me; during one interview I felt I could not avoid crying, so I took five minute break to calm myself. Following this interview, I wrote that "this person is really a survivor, and I am so happy to be able to share in this experience even though it's really sad and I am choosing to focus on this participant accomplishments instead of their struggles".

Member (participant) checking. After I had completed the transcription of the recorded data, I contacted all participants for a follow up meeting to review their transcript. Unfortunately only two of the participants came for the meeting to review their transcript. I met these two

participants at PLN after members support meeting and reviewed the transcript. Five participants in this research did not respond to phone calls and email messages and after 3 weeks of trying to get in touch, I proceeded with coding. This is understandable as sometimes members are sick, or busy with other activities, and at times stay away for a period of time. So I proceeded with the research under the assumption that no change was needed

Ethical Considerations

This research was conducted within the defined ethical parameters of the UNBC Ethics Board. Ethical approval was sought from the Research Ethics Board at the University of Northern British Columbia (see Appendix F). PLN provided a letter of support to conduct the research at their location.

Although there were no major identifiable risks for participating in this study, a couple of considerations were kept in mind when dealing with PLWHA. The following safeguards were used to protect the participant's rights:

1) Participants were advised IN WRITING and in face to face conversation of the voluntary nature of their participation (see Appendix F) and that they can withdraw from the study at any time without penalty. They were also advised that at any time during the process they could decline to answer any question.

2) The research objectives were clearly outlined IN WRITING and in face to face conversation and articulated in simple terms to the participants.

3) A written consent form was obtained from each participant.

4) The participants were informed in writing and in face to face conversation of all data collection methods and activities.

5) Provisions are made for monitoring the data collected to ensure the safety of the participants.

6) Written transcriptions of the data were made available to the participants.

Summary

In this study, a hermeneutic phenomenology framework was adopted as the most appropriate choice to explore the phenomenon of persons living with stigma and resilience. It has the advantage of offering opportunities for rich data collection from a population that tends to be silent (Creswell, 2007). According to Patton (2002), phenomenology explores the "meaning, structure, and essence of the lived experience" of a certain phenomenon, for a "person or a group of people" (p. 104). This was the most appropriated method in understanding the essence of person living with HIV-related stigma. Bran and Clarke (2006)'s six phases of thematic analysis was the method used to analyzed the data. The six phases of thematic analysis included: developing familiarity with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. The themes and sub-themes revealed through the data analysis will be discussed in chapter four.

Chapter Four: Findings

The findings presented in this chapter are based on the lived experience of PLWHA in Prince George. This chapter outlined the findings based on the analysis of the participants' interviews. The questions used during the interview were asked in order to gain knowledge and understanding of individuals stories and in the process acquire information about the experiences of PLWHA.

The chapter begins by detailing the demographic characteristics of the participants. The second part of this chapter focused on the stigma experiences of participants. In this section, it is my aim to provide rich detailed experiences of individuals, in order to convey participants' experience, as this will add value and depth to the findings. From this, I discuss the themes that emerged from participants' experience. In doing this it is my aim to answer my research questions. The third section focused on the various challenges that are faced by individuals that have emerged from the interview findings. Also, the responses of participants to their diagnosis and stigma were highlighted. Finally, the factors that contributed to resilience and the impact on participant's self-care will also be presented in this section.

Demographics

Demographic information was derived from a short survey that I gave to participants at the beginning of each interview (see Appendix D). The demographic information that was collected contained details about the participants' employment status, educational background, and living arrangement among other factors. All of the participants completed the basic demographic questionnaire and the information is summarized in Table 1. It should be noted that sections of the demographic information are not presented in the table due to the topic of the

study, the small sample size, the population size of Prince George, and most importantly to protect the anonymity of all participants. Of the seven participants, four identified as male and three as females with the ages of the participants ranging from 27 to 52 years old. Five individuals self-identified as heterosexual, one as transgender and another as gay. Of the seven participants, three identified as white/ European, and the remaining four individuals identified as Aboriginal/ Metis/ First Nations. In terms of housing, six of the participants lived on their own and one participant lived with friends. As it relates to educational background, four participants had acquired a high school education and the remaining three only had acquired an elementary education. Looking at employment status, all seven participants were unemployed. Interestingly, there were no newly diagnosed female participants; all the female participants had lived with HIV from 6 years to greater than 21 years. On the other hand, three male participants had lived with HIV for less than 5 years and the other male participant was living with HIV for over 11 years.

Table 1

Demographic Profile of Participants

Number	Sexual Identity	Living Arrangement	Education	Job Status	Time period of Diagnosis
01	Heterosexual	On Own	Elementary	None	6-10 yrs.
02	Heterosexual	On Own	Elementary	None	< 1 yr.
03	Heterosexual	With friends	High School	None	< 1 yr.
04	Heterosexual	On own	Elementary	None	1-5 yrs.
05	Heterosexual	On Own	High School	None	11-20 yrs.
06	Gay	On Own	High School	None	11-20 yrs.
07	Transgender	On Own	High School	None	>21 yrs.

Lived experiences of stigma

The major themes that were derived from the thematic analysis relating to stigma experiences were enacted stigma and felt stigma. For the purpose of this study, enacted stigma refers to discrimination based on ones HIV status. Felt stigma is a broad term that refers to both internal stigma and anticipated stigma, and includes perceptions of stigma, fear of stigma and the negative perception of self.

Enacted stigma. In this section, I present findings under the theme of enacted stigma. The sources of stigma were classified under two sub themes: stigma from family and friends, and stigma from the workplace.

Stigma from workplace. During the interview process, three participants shared an experience which addresses the theme of enacted stigma relating to the workplace, where respondents were treated poorly or fired because of their diagnosis. Of the three, two participants disclosed that they were fired from their jobs. For participant 6, he was treated poorly by his employer and was eventually fired for what he believed was his HIV status.

> When I was down in Vancouver, I got a job working and when my supervisor found out about my HIV status job . . . I don't even know how he did, he started to find fault with everything thing I did, soon I was getting frustrated and he eventually fired me . . . I know it is because of my status (Participant 6).

Another participant shared a similar experience. In this case, Participant 4 had chosen to disclose his HIV status out of concern for the safety of his co-workers because he thought this was the best decision. He later regretted this decision since it resulted in his termination.

> I used to do crab fishing and I usually make pretty good money and in the winter I do fishing. I worked on the dock lowering crabs and I kept really busy and some years I didn't have enough time to collect EI [employment insurance]. After I found out about my HIV, I decided to let the people that I worked with to know about my status . . . They didn't want me on the boat anymore they were scared of catching it [HIV] so they didn't call me to work anymore more... they didn't even talk with me, they didn't even give me back my rain gear and other stuff on the boat, maybe they throw it away, or I don't know what they did with my stuff but I went down to the boat to get my stuff and it wasn't there anymore. That was last time I had a real job (Participant 4).

Additionally, Participant 7 reported that employees treated her differently once they found out about her status: she eventually decided to quit. After receiving training in a field that she was passionate about, finding employment so far as proven unsuccessful even though she has applied to numerous jobs. Only two of the prospective employers responded, and requested an interview. Following these interviews she was praised for her good interview skills and knowledge of the job, however there was no job offer.

> I have applied at numerous [place], and even applied at a particular one 4 times and I did three interview's and each time I see them hired 4 – 5 people from the same courses that I completed, imagine I tried for 4 times and did 3 interviews and all 4 times I never got phone call back, I never got nothing. Couple of the interviews I did they said they would call [me] back and that the interview went well, but nothing. I am qualified yea, I have my food certification, serving it right certificate, I did couple [other] courses and yes I have been denied every time I apply. I know it's because of my status because I'm out in the community, and I am associated with PLN. It was same as before earlier in my diagnosis I had a job and when they found that I was HIV positive the staff would treated me badly, and I just quit. I am still always looking for more . . . courses to do it is my passion, but I know I will not find any job (Participant 7).

Other participants expressed similar concerns relating to lack of employment and the challenges they encountered finding unskilled labour. This was a topic expressed by all participants since all were unemployed at the time of the interview. Although laws prohibit discrimination in the workplace, participants reported constantly experiencing enacted stigma in the workplace.

Stigma from friends and family. All of the participants' interviewed discussed the

various ways in which family and friends responded to their diagnosis. From the interview process it became apparent that some family members and friends had limited knowledge of HIV. In many cases, the family and friends were shocked, or scared, among other reactions. Overall, these reactions by family and friends negatively impacted their relationships with the individual. Family members and friends responded mostly out of fear of contracting the virus. Respondents articulated that although some family members communicated that nothing will change and everything was copacetic, family members still stigmatized them by not showing love or any support. Participant 4 reported two main stories. He expressed that most of his friends abandoned him; they didn't want to be around him or even do activities with him.

> Being in a small town everybody pretty much found out . . . and the door started closing. They didn't want me around you know, the little local corner store I used to go to hang out and sit and play keno and stuff, they didn't want me in the store cause people were bitching he shouldn't be allowed to hang around here cause he got HIV and I buy my food from there and stuff . . . some people were complaining about me being around like food and stuff so they try and push me away. People weren't being friendly, I was losing friends slowly you know. . . I would phone them up oh what you are doing today, I'm busy and I would ask oh you want to go do this this weekend or that this weekend and they would always find an excuse why they couldn't go hang out with me. It changed a lot of people they didn't want to be around me anymore so most times I was alone (Participant 4).

Participant 4 shared a scenario in which his family treated him differently because of his diagnosis. Even though the respondent was told that he would be allowed to interact with his

nephew and niece, however activities with his nephew and niece were restricted out of concern for the safety and health of the children. This impacted on his relationship with his nephew and niece.

> My other family members didn't want me touching my nephews and nieces . . . they were worried about me getting the children sick . . . it was pretty hard I couldn't play with my niece and nephew . . . when I stayed over at a my brother's house when the kids wake up . . . they wanted me to cook something for them . . . after my family found out they didn't want me to touch the kids food anymore . . . they were scared you know maybe I get the kids sick from me making breakfast . . . and it was hard for the kids to understand why I couldn't make them something . . . my brother would say, we don't mind you being in the house we love you but if the kids needed food we will do it . . . the kids couldn't understand why uncle couldn't cook for us anymore, it hurt deep down not being their uncle, but what could I do (Participant 4).

Participant 1 also talked about a friend who treated her differently, once she found out about her HIV status. Her friends had expressed they didn't want to show any affection such as hugs and kisses out of fear of contracting the virus. This affected the participant psychological health, where she felt like she was alienated and invisible.

> I got so used to being a ghost, where I'm not real. I have been treated like an outsider where people treat me badly, they used me, and this was even worse after my diagnosis. It felt I was not human, or I didn't exist so I figure I must be a ghost. Person refusing to come close to me or even hug me at times and I know is because I'm HIV positive so I figure I must be invisible (Participant 1).

Another aspect of stigmatization involved people passing judgment on individuals whereby labels were attached to the identity of the individuals based on assumptions that transmission might had been related to sexual contact or IV drugs use. For Participant 5, individuals had made judgement based on what they perceived was a reprehensible lifestyle.

> Yep stigma is still a big problem because people continue to try and make you feel like nobody, alone and sad and just make you feel more depressed as if you're not dealing with so much struggles and shit in your life. People with cancer . . . get treated with respect; with my immune system I could have cancer and other stuff, because I'm immunocompromised, because of HIV. If I die they will think this person die of HIV and not that my immune system is low and other sickness, because all they see is HIV, is like they are always judging you . . . is like something goes off in their mind, and maybe trying to figure if I fit one of the category, if I'm drug addict, if I'm a lesbian, or a prostitute, or some shit like that and or that I'm dying . . . not realizing with HIV people are living fulfilling long life with improvement in medication and science. If anything it's the stigma and discrimination that is killing people the most, because of how people treat us shitty. The way people behave or treat you because of your sickness it's like you're always going 20 steps backward (Participant 5).

Lack of education about the HIV virus and transmission resulted in fear of contracting the virus. As a result family members and friends would try to protect themselves by decontaminating surfaces with bleach, or washing cutlery multiple times after use, or refusing to drink out of the same container as the participants as a method of keeping "safe". Participant 6 shared his experienced as it related to this phenomenon.

> It was when I went home to visit her [mom] in summer; I didn't stay at her house I stay at my younger sister's place. But there were couple of nights when I stayed at my parent's place and I slept on the couch . . . my mother would put sheets on the couch and give me certain blankets and stuff . . . after I get up in the morning . . . she would grab all those stuff and throw them in the washroom with bleach and whatever disinfectant saying she don't want me to spread my virus, she thought I might leave it on the couch. Oh silly, yep (Participant 6).

Participant 3 shared similar experience of being discriminated by friends.

> Yeah a couple of times some people who knew I had HIV and I offered them water and they wouldn't drink out of my cup . . . these were the said people who drank out of my cup previously . . . they would say no thank you and look at me weird, so I just laugh, and I say whatever more water for me (Participant 3).

Felt stigma. Felt stigma was another form of stigma that was shared by participants. Most of the participants had experienced some form of enacted stigma, some to a greater degree than others. Most participants reported fear of possible stigma from family friends or even the workplace. Fear of stigma was common among participants who had experience prior stigma resulting in constant anxiety that they might experience further stigma. For Participant 2 who was newly diagnosed (less than one year) he anticipated stigma based on the experiences of other participants who had shared stories of enacted stigma. As a result, he decided to hide his diagnosis.

> I look and appear healthy most of the times by regular exercise. I walk everywhere, I try to eat nutritiously, a well-balanced diet despite some bad habits,

> so I can look healthy . . . because I keep the fact I have HIV sheltered and hidden so well, right . . . I want to keep it a secret as much as possible, whenever I come here to positive living north I try to make sure that if anyone I know is near the building I don't access the building until the person is out of sight because, I just don't want people to find out, sometimes I even enter from the back . . . because HIV is a deadly. It is much stigmatized and just a deadly disease that a lot of people fear. It is one of the most highly stigmatized and feared disease known to man is HIV, so why wouldn't I want to keep it a secret from a good majority of people I come in contact with. I'm tired of being treated differently. So to be treated like everyone, I just keep it to myself, it is life threatening and is associated with certain things such as homosexuality. Certain type of drug using, promiscuity, that sort of things and I know people will automatically attach a label to me (Participant 2).

Additionally participant 7 feared being rejected due to his HIV status and prior experience of being rejected by his sexual partners.

> Men I would normally be attracted to I sort of stay away from them out of fear of being heartbroken if they come on to me, knowing if I explain to them my status I know they will want to stay way, how would they be able to deal with it so it affect my chances of having any partner and finding love I mean it has done lot to my personal life (Participant 7).

Another sub-theme of felt stigma was discussed by participants was the topic of internalized stigma. Participants experienced shame, blame, and feelings of guilt. Participant 7 shared:

> Being positive have affected my life in every way, like I was scared and afraid, scared to really have sexual partner and enjoy sex, you know the fear that I might pass the virus to someone else (Participant 7).

The feeling of guilt was also expressed by participant 5, where she expressed fear of passing the disease to her sexual partners.

> I blame myself a lot times for my diagnosis, thinking maybe I deserve this shit... and the guilt at times too, when I think of dating someone and then finding out they contract the virus from me and coming back to hurt me or something, I just couldn't live with myself if I know I did that (Participant 5).

In summary, participants faced both enacted and felt stigma. It was noted that the youngest participant who had HIV for the shortest period of time who learned from or observed PLWHA's experience of stigma and discrimination through the 1990's choose not to disclose his HIV status due to fears. From the research findings individuals who were diagnosed for a longer time period had experienced more enacted stigma comparing to felt stigma and it was a constant battle for these individuals to protect themselves from further stigmatization. Six of the seven participants had disclosed their status and were living their life in the public eye.

Challenges

Participants in this study experienced various challenges as a result of their diagnosis and due to the impact of stigma. The main sub-themes that were identified under this section included: relationship, financial, drugs, mental health and disclosure.

Relationship. Most participants (n= 6) talked expressively about being lonely and not having a relationship due to their HIV status and associated stigma. Participant 2 reported feeling lonely due to a lack of a committed relationship. The participant is actively seeking a partner to find companionship, love and the possibility of wife and a family, however this has not proven successful thus far, and he is hoping that this will change in the future.

> I mean if I don't have children, a common law girlfriend or even wife to look after and just to have someone to love and be around, what's the point of life? I really want to start a relationship at this point in my life since I'm in my late twenties . . . I never really walked into girls in my life that I became significantly, emotionally attached to, someone to love and called my wife, you know a normal life . . . one with a wife and children, living the normal big happy life (Participant 2).

Similar sentiments were also expressed by participants 5 and 3 where finding a life partner was a difficult and daunting task. Participant 5 reported that, all she desires is unconditional love, a partner that can see beyond her diagnosis and will treat her like a human being.

> I have reach a point that I find the hardest is educating people or hoping to find a relationship with somebody that is accepting, loving, understanding . . . love me unconditionally that will see me and not the virus. I am not the virus I am a loving beautiful human being. I am a person and longing to find someone that will see me as a whole (Participant 5).

For participant 3, the lack of a committed relationship have affected him psychologically, making him feel less of man, since he find it difficult to have conversation with members of the

opposite sex. Before a positive diagnosis, this was never an issue but now he is always faced with the thoughts of rejection, or the impossibility to find a partner willing to commit to someone with an incurable medical problem.

> Being positive makes me closed off towards women, because I have to tell all the women if I want to sleep with them . . . it is embarrassing when I finally meet a nice looking girl I have to tell her that I have HIV and I know it won't go any further they pull away from you. There is that and it does something to a guy's head, difficult . . . I used to have a lot of girlfriends and never have problems talking to girls or having girlfriends, that's was never my problem . . . now that I have HIV I have a problem dating girls and even talking with girls and just having a relationship, this is just really hard for me (Participant 3).

Similarly, participant 6 stated that the lack of a relationship was a difficult challenge he had to deal with earlier in his diagnosis. However, years have passed and he has grown accustomed to single life and is pessimistic about future relationship.

> When I was first diagnosed . . . it was hard for me not being in a relationship and able to express my love physically, and otherwise, now it's doesn't affect me. I just accept that I'm single and it will be like that for a while, it comes with being positive (Participant 6).

Financial challenges. Another obstacle that was a concern in participants' stories was, financial instability impacting on their resources. Participants were generally living on disability income and or a low income provided by the government. They complained that the income was insufficient and thus they were not able to enjoy certain privileges such as driving a car, going

out for dinners, or even to afford basic necessities such as owing their own home or affording healthy food. This resulted in feelings of anger, and frustrations.

> Not having a job make me feel mad and I'm pissed, I do not have money to do the things I want. I feel like why I should even try, I mean because I know I am able to do the work (Participant 2).

Another participant was living in low income housing, in an undesirable neighbourhood, and was not able to afford basic items or even items that would add to his comfort and convenience for example, a car. This contributed to him being dissatisfied and unhappy at times.

> I appear as a man with money making resources and capabilities . . . my disability pension allows me to have very little money. I went from a full time employee, a contributing member of society to what people would call to be a welfare bum. I was stuck in low income housing and shelter since this was only what disability pension could afford, so there is little I can do to enjoy the finer things of life (Participant 2).

For participant 4, he saw a drastic decrease in income and this impacted on his independence, and his ability to provide for his basic needs. This was difficult for him to adjust or survive on little or no income.

> I was screwed: I had a good job, making good money and now here I am being on welfare . . . I went from having 40-50,000 dollars a year to throw around to having 200 hundred dollars to live on . . . That's what I get from welfare after my rent is paid, I get 200 and something dollars, that much I have to live on. I don't have disability or nothing. It was really hard to adjust and I'm still adjusting, I

> think . . . I think I'm doing okay, but I'm not. Financially it's been so hard for me, you know . . . Like I said, I was making so much money but now, no job, and no money (Participant 4).

Disclosure challenge. Another challenge experienced by participant was disclosure of their HIV status. The decision to disclose, or not to disclose and who to disclose were important decisions in participants' lives. Disclosure of one's positive status was associated with fear of stigma and further stigmatization. Disclosure for the participants came in several forms: from telling people directly (intentional disclosure), by associating with professionals who work with HIV/AIDS agencies and by attending facilities and medical clinics that work only with person who are HIV positive (accidental disclosure). For participant 6, disclosure was clearly related to fear of stigmatization.

> I really kept it to myself but when I moved to BC . . . my sister was living on the Island so I went to see her . . . I went and told her but I could not tell her when I was sober it was too hard for me to say the words, so I took her out [party] and we were drinking . . . I was drunk and that's when I told her I was HIV positive, I didn't know what to expect and I was too afraid (Participant 6).

When disclosing HIV status, participants also had to contend with the issue of trust, whether they will be able to trust the person with the information given to them. For participant 5, this was an issue she had to deal with, where her mother went against her wishes and disclosed her status to her entire family and friends.

> I didn't want to tell anyone, I didn't know who to trust, but then I decided to just tell my family, and I told my mom not to tell anyone and when I get back to [the

> community] basically every fucking one knew I was positive . . . I didn't get a chance to keep it a fucking secret or nothing . . . my mom told everybody, so it was no longer a secret and I was never ready for to be out (Participant 5).

Participant 4 expressed regrets in disclosing his status due to stigma, and other negative impacts he had to deal with which initially made it hard for him to adjust.

> Because I was honest about my sickness when I first found out I told my best friend right away . . . the only time I talked about it was when I was intoxicated. It [HIV diagnosis] was something I really didn't talked about when I was sober, I couldn't handle it [HIV] was too real . . . I was so embarrassed and ashamed about it. Looking back I was wondering if it was worth telling people, for the way people treat you and losing so much, but I guess I get to know if people are true (Participant 4).

Recreational Drugs. Another recurring theme was the use of illicit drugs which was a major challenge for all seven of the participants interviewed. Illicit drugs were commonly used as a coping mechanism to alter the effects of negative feelings, and other challenges. It was noted that while drugs use was a challenge for some participants, others use drugs to cope with challenges. Participant 1 discussed that it was hard to quit, as the use of drugs was a method of survival for her.

> I have had problem with my drug use . . . being a drug addict for so many years it was hard to kick . . . The drugs are constantly calling my name, I can't stop that from happening but it's that constant calling, and sometimes I just need something to help me deal with everything that is going on. It is just so hard to

> deal with everything . . . (Participant 1).

The use of drugs to fill the emptiness caused by a positive diagnosis was common to many participants:

> I said to myself wow you're telling me [that I am HIV positive] and I was high that day because I didn't know how to handle things when I went in there totally whack on cocaine . . . you're alone and scared or whatever and you will do things to fill the gap . . . that's was drugs for me . . . I took crack and it got worse and worse and I started injecting. I tried everything at least once . . . if I didn't like it then I stop. That's me. I tried it all, it was the thing to turn to . . . drugs was my comfort (Participant 5).

For participant 7, the constant use of drugs helped her to relieve physical pain and cope with everyday challenges:

> Health care is good to a degree but if you are an ex-addict or on methadone, they will not give you pills [pain meds] when you are in pain. I am telling you sometimes I am in pain, physically, as well as mentally and they won't give me a pain killer. They tell me no, because [the pain meds] is bad for my liver and then they won't give me the other pain medication . . . Where am I supposed to get pain medication and all that's bull shit. I don't care what the doctors and nurses say, you know it's my body and I know when it dies . . . who knows me better than me, who knows my body better than me? I mean no doctor can tell me because when I am in pain and they don't want to assist me I will go buy some pot or some pain meds on the street so that's where I get my drugs on the streets, it keeps me going I need it to survive and deal with life . . . (Participant 7).

Mental health. A common challenge reported by participants was mental health problems such as: suicide, fear, anger and hopelessness, and this resulted in additional challenges. Mental health problems were commonly experienced by PLWHA due to stigma, and the challenges associated with living with an incurable chronic condition.

Suicide. The issue of suicide remained omnipresent in two participant stories, as a response to their diagnosis. Participant 2 struggled with suicidal thoughts and other mental problems. It was a constant battle for the participant. To resolve his negative feelings, participant 2 was getting psychiatric help at the time of the interview.

> There were times where it was very tough where I was borderline suicidal and there were some days, I struggled with my internal feelings of having this disease. I get borderline suicidal . . . I am thinking at times I just want to put a bullet in my cranium . . . I just didn't know how to deal with all of these feelings, but now I'm getting help, but the feelings do come . . . (Participant 2).

Similar thoughts of suicide affected participant 5 who sporadically struggled with negative feelings. The respondent had daily encounters of varying feeling such as despair, anger, and hopelessness. The participant at times felt like giving up, since the pain accompanied with a positive diagnosis was unbearable.

> . . . Sometimes suicide crosses my mind. It's a beautiful day and you don't even think you have it and other days you just don't want to live, you just can't deal it with anymore . . . that's why having denial for so long kept me going. It has taken me 13 years. I was denial for the first 8 years that I have it . . . yep 8 years of

> having HIV. . . There was no fucking way that I had HIV . . . The shit I experienced the whole of my life and now I got this . . . (Participant 5).

Fear. A concern expressed by most participants when faced with the news of their status is the fear of dying. This was eminent with the younger participant, where previous to their diagnosis, death was never a concern, but upon hearing their diagnosis HIV mortality becomes a reality. For participant 6, the fear of dying was prominent in his life.

> . . . There was a psychological thing like a fear of dying, because I don't have family [here] they all are up in [my home community] and stuff like that and it was always a challenge for me every time. I get like a cold or something and I was wondering . . . is this time I am going to die . . . and every time someone died I wondered if I am next . . . I was scared of dying, because I didn't know when I will die, or where I will die as that was always on my mind. Lot of people I knew that were already positive that they did not have HIV but they have AIDS but they were in like pretty bad shapes so I was scared, that I was going to look to like that (Participant 6).

Upon hearing her diagnosis, the thought of death instantly came to participant 5 mind: feeling of hopelessness, shock, and fear of dying. Prior to her diagnosis, the only thing that was associated with HIV was death and despair; thus upon hearing her diagnosis death was a major concern for her.

> So immediately I broke down in tears in the bathroom . . . I was crying out oh my GOD oh my GOD . . . I am going to die I am going to die I am going to die [tears

> in eyes] . . . because I never thought I could die this young, the thought of death is something I know I will always have to deal with (Participant 5).

Similarly the fear of being alone, or even going to sleep and never waking up was a challenge that participants had to deal with. This was a struggle for participant 7:

> There is fear of being alone and dying all alone; sometimes that fear will come and all of a sudden knowing how many people have passed away over the years . . . I have known some here at PLN and the fact how fast people die when it comes on to HIV and it turns to AIDS instantly, sometimes you wonder if you're next (Participant 7).

Similar sentiments were expressed by participant 4 who had trouble sleeping, and had fears of dying alone.

> I get scared sometimes and I have a friend who comes and stays with me some time because he's scared to go to sleep at night, because he won't wake up and he feels like that, he is positive too and he gets scared some nights to go to sleep because his brain wont wake up and I was like that for a while too, afraid to go to sleep and never wakening, but I'm glad to have someone around (Participant 4).

Additionally, other mental health issue that respondent dealt with was anger. Participant 1 reported severe anger at times which resulted in me hating everyone.

> I was not happy but when I heard about my diagnosis. I hated everybody I hated the world it was just so hard (Participant 1).

For one participant it was so hard to deal with his diagnosis: he was constantly feeling sad and hurt.

> Tears came to my eyes and a lot of sadness, anger despair just a lot of emotions. I was just mad at myself and just with life (Participant 2).

The issue of hopelessness was also accompanied with anger.

> I see my future as kind of bleak I guess you can say where there is really no light at the end of the tunnel no really bright shinny star that I could grab a hold of and sing a way with . . . it is really difficult to not just want to party it up its very difficult because knowing all these information [living with HIV] is like sticking all these huge boulder stone on each foot and expecting me to keep walking, how do walk when you have such much to deal with (Participant 3).

Response

Participants responded in variety of ways to stigma and the various challenges faced such as educating themselves and others, faith and resilience. The positive response by the participants resulted in acceptance, giving back or activism work, taking better care of self and overall personal growth.

Educating self and others. Participants faced stigma from various sources, from family and friends, from the work place or community members. As a response mechanism, they decided to either educate those from which they experienced stigma or channel what they learned from this experience to educate and help others learn more about HIV, the mechanism of transmission and the challenges that they face on a daily basis. Additionally, participants made

an effort to educate people to whom they revealed their diagnosis. Several participants spoke about the importance of education in managing stigma. For one participant he learned how to better care for himself physically and learned about the various indicators that where necessary such as, cd4 and viral load, that helped with the management of the disease.

> I have a big book on it [HIV] and I know a lot about it now and more comfortable with having it now . . . A friend of mine in detox he had HIV and he gave me a book called people living with HIV. Yes for sure I learned a few things . . . One section I had learned about since I didn't know, where it talks about cd4 and viral load and that if you have a low viral load it's harder to pass the virus on . . . It also helped my friends a lot because I would share the knowledge with them and now knowing all the information, it makes them more comfortable (Participant 3).

Similar sentiments were shared by another participant. He was thankful for the education that he received, because it helped to demystify the myths surrounding the spread of the virus.

> . . . Just the way I think when I was first diagnosed, that I could infect people if I touch them or hug them, I feel a lot better now because you know back then I really didn't know anything about the virus, it was just the negative, but I read all the books and everything I could get information about because I wanted to know more, and looking back now I am laughing that I could really think those stuff . . . (Participant 6).

In addition, education played a key role in educating friends and family about the disease. This is helpful in stigma mitigation, and improving the care of respondent.

> I went to a nurse whom I knew for a long time, and she worked at [local] needle exchange, and she explained a great deal to me and my doctor. When I told them [family and friends] about the stigma of HIV and explain to them how it will be caught and spread and they were sort of relaxed around me, they were ignorant so I had to teach them . . . I told some people in the community, they asked me a lot of question. I did this because I wanted to educate people about HIV, since they lack knowledge of what the virus was really about (Participant 1).

Similarly, another participant believed education was a key component to limit the stigmatization that is accompanied with having the disease.

> . . . Learning and educating self and others is the important piece or component in getting the message around about HIV. . . I have recognized it is always a learning process and that's what helped me, knowing more about the disease and what to do to take care of myself, and being healthy (Participant 3).

Resilience

The topic of resilience emerged in the data as a response mechanism. Although participants had endured hardships, various challenges with jobs, income, relationships, drugs, they still had determination to succeed in their endeavours and described a sense of facing the future with optimism. The three themes related to resilience that emerged: support from family and friends, support from organizations, and the inner resources of the participants. Resilience has been defined as a capability to positively adapt to circumstances despite significant adversity, or, in the simplest form, being able to bounce back after adversity and struggles (Tugade & Fredrickson, 2004). Participants demonstrated resilience in the face of the stigma they faced and

became stronger in the process. One form of resilience demonstrated by participants was their inner qualities, such as optimism and faith.

Inner resource/ inner qualities. This theme refers to participants' internal qualities such as optimism, hope and faith.

Being positive/Optimism. Optimism was a quality that helped participants focus on the future and not on the negative. The theme of optimism encompassed having a positive outlook on living with HIV and remaining hopeful about one's continued well-being. Optimism played an integral in the fighting spirit of few of the participants.

> I don't have bad days anymore [laughing] every day is a good day . . . I am alive and I have come this far and survived a lot of trials, so for me every day that I am alive is a good day. I am finally comfortable with who I am because growing up I was really abused, physically, mentally [and] sexually. I was really abused and it brought me into a shell . . . like now I am pretty open about everything and I decided to think positive about things, because my life is going good . . . in the right direction let's say I have a purpose so I focus on all the good . . . (Participant 4)

For participant 7, being optimistic in spite of the various challenges and barriers she had encountered, was the one thing that gave her meaning in life.

> Finally, one morning I woke up and I said enough of this crap, and I said enough of the thinking of death and dying, so I went up to the bath and I looked at myself in a mirror and I said I am going start living with this, I am going to start learning

> more about HIV and hopefully you know things will get better and it did (Participant 7).

Having hope and being optimistic as helped participant 2 in choosing life that has purpose.

> The way I see it . . . I see my life as journey and yes I have struggles, and yes I have addictions and bad days, depression, but I am choosing to live, holding on to that maybe, that maybe is what is keeping me going, I have come from a far way . . . so yep I'm resilient (Participant 2).

Additionally, being optimistic helped participant 5 realize that having a HIV diagnosis has helped her on her journey. Although HIV is an incurable disease, participant 5 believes that her diagnosis helped her in many positive aspects, such as: a change her in her overall outlook on life.

> HIV is definitely not a death sentence that it will give you a new life . . . if you want to . . . look at it and see that something better can come out of it, yep out what is seen as deadly virus, comes something better (Participant 5).

Faith. Faith in a higher being provided participants with hope. For participant 6 her faith had positively impacted on her journey this far living with HIV.

> My mother she is a religious lady so she is always praying, praying for me and other people who are living with HIV, hoping for some miracle or healing . . . and at time I ask her, remember me in your prayers . . . she is always happy when she hears that I am doing fine and healthy and whatever, I guess the prayers are working and helping me (Participant 6).

Spirituality played a major role in the journey of participant 7, where a belief in a higher power helped her through difficult periods in her life.

> When I first was told about my diagnosis, I was really sick . . . I mean like full blown cancer that affected my spinal cord which was healed by God . . .so I gave my life [baptized] to God and he is been helping me in this walk with HIV. . . . even my husband that passed away, it was really hard being alone, was torn inside, but God was there for me, telling me to keep going and live . . . I want to live for as long as God has something in store of me . . . that's why I quit the drugs, that's why I quit the smoking, to improve my health. I was totally lost, and I didn't know which way to go and I didn't know where to turn and I hang on to God, he provided me with the strength and power to continue (Participant 7).

Inner strength and peace was another quality that participant 5 found as a result of spirituality.

> My inner strength comes from a higher power or some being watching over me, don't know what exactly it is and where it comes from, but something just telling me to go on and it just lifts all the negative and bad stuff from me. So I just try to be good and it comes back to me (Participant 5).

Support from families and friends. In spite of the various trials and stigma, love and support from some family members played a vital role in participants 'bouncing back'. All participants in this study had disclosed their HIV/AIDS status to family and friends. However, only few family members and friends provide support and helped to empower PLWHA to manage and combat stigma. Participants received different kind of support from sources to whom they revealed their diagnosis. This support ranged from a simple acceptance of their

diagnosis, an acceptance that was free of any stigmatizing reaction; to more active support in helping participants to access resources and combat stigma that they may have faced from other sources. For one participant although other family members rejected her, it was her father's love and support that kept her going. Participant 1 considered her father as her hero, the person that gave her strength and courage:

> My dad he has never changed in the way he treated me . . . as a matter of fact he treats me even better now, where he spoils me . . . if my dad dies, I hope he dies before me and I tell my dad I can't see a life after he is gone . . . he said that's not the way it is supposed to go . . . I said that's the only way I could survive. My dad he is the one that have been there for me, my dad is only one in the world where is opinion matters. My dad is my knight and shining armour and as long I got his love and support that's all I need he is my [crying] everything (Participant 1).

The love and support that participant 5 received from a friend made her feel loved, accepted and supported.

> One person I told that absolutely loved me, adored me and accepted and took me in [living with them], made me know what it was to be truly loved, unfortunately he is now dead. He was like you're so beautiful inside out and loved me unconditionally, that was so beautiful. I was in a good place but it lasted for a short while, he was my biggest supporter (Participant 5).

The workers on the street became the biggest supporter for participant 7, and eventually became her family, as her biological family neglected her.

> Oh my family was never supportive, but I carried on my very way and just figured

> they are not worth it. I mean if people are willing to stand by me then those are my family, people that I work the street everyday with, those are my family, I mean my friends . . . those are my family. They all accept me and support me (Participant 7).

The general reaction of friends and family for one participant was that of support and love: it made the transition easier.

> As far I know [my family and friends] seem very supportive, trying to help me, it's not as bad as I imagine 20 years . . . My closest family and friends provided support, so in a sense that's positive . . . I know who my true friends are and some of them have really stuck by me through it all . . . some not as much but as I said I eventually figure out my true friends (Participant 6).

Support from AIDS service organization (ASO). An important part of resiliency is the support from external sources, in this case ASO. The organization provided participants with services, food, and resources to better equip and to help participants during a challenging period. In addition to re-establishing ties to family, participants also developed important connections with community and agencies. In this research the vital role of ASO was an integral part of participants' physical, emotional and spiritual growth. Participants sought out membership in various support groups one of which was PLN and received guidance and advice from fellow members on how to deal with possible stigma. Support groups consisted of person living with HIV and would share stories. Participants attended support groups to discuss their problems and experiences of stigma, share success and to have a sense of purpose. Also, they sought advice from members of the support groups on how to face stigma and to minimize its impact, coping mechanism, or just to provide and hug or shoulder to lean in times of need.

> Well Positive Living [PLN] has taught me a lot, it gave me the opportunity to talk with others both HIV positive and negative individuals sharing my experiences and also I work[ed] part-time here at PLN as a peer support worker but I took time off until I am done school (Participants 6).

The staff members at PLN for participants 1 and 7 were more than just workers, they were family.

> Being a road warrior [person living with HIV working as peer educator], PLN, now I have a family that really care for me and love me I can always go to my mom [name of a counsellor and other staff], between here and the fire pit [drop in centre] those are the people that I love and care about they are my family (Participant 1).

> Oh yes they have helped me to carry on [PLN] and native health [a local clinic] . . . these are the only people I have in my life, they are good people, different from others. I spend a lot of time in this room [member support room] where I thought I was really going to die, where I just reflect and mediate on how I am going to survived this and carry on . . . I just love here it's my place it helped me through some of my darkest time (Participant 7).

The support from ASO helped participant 5 to have a positive outlook and realize that being HIV positive was not a death sentence. This positively impacted on her self-image, and overall view on life.

> ASO like PLN they show you another way of living that it's more socially acceptable, that there is so many more other people living with [HIV] you're not

> dying because you're positive . . . You have to learn to love yourself and accept it and that you have people to show you day by day because you're never going to learn this overnight. It took me thirteen years to finally just realized I love my self, to realize it's okay, it makes me stronger, and to take better care of myself in long run . . . people who don't have HIV go out there and beat themselves up with drug and stuff, but I know I have HIV so I have to have my limitations are I will end up in the hospital a gain (Participant 5).

Providing a safe place was also another important component of service organizations. The respondent felt a sense of security and felt comfortable confiding with workers at these institutions.

> PLN helps me, PLN is a place where I get all my negative emotions out and issues out in a safe place in a safe way. PLN has a been a great help, helping me to realize my true potential and my self-worth . . . it's who I am, a human being and not a statistics or a client or patient but a human being (Participant 4).

Another important function for service organizations was providing access to doctors making appointments, providing food hamper and essentials. This has proven helpful, since the resources of the participants were limited due to lack of a job and no financial support.

> PLN is a big part of me coping . . . I try to watch a movie or something else to keep my mind off the problems or challenges that help . . . it takes me away from reality and keep my mind off HIV . . . and it helps me to stay clean and not get high. The aim is to keep my mind off stuff or else it would drive me nuts . . . . they do all sort of stuff . . .housing list . . . help to find housing, bus ticket, food

> phone just about everything . . . Everything in this place rock, they definitely do a lot to help me (Participant 3).

Another important component of the support organization is providing education and training to empower individuals and to prepare participants to work as peer support workers, positive prevention warriors where they educate both HIV positive and negative individuals.

> PLN educated me about the places to go for social services, disability support. There was so many different options that they informed me about, there was lunch, there was a place at PLN that you could come hang out having persons coming in to give flu shots, and the trust they build with us individuals . . . and also the options to livelihood so you didn't have to think you just sit at home and live by yourself, alone. I even have worked here (PLN) as a peer support worker and travelled to different province to meet and talk with other people living with HIV. That connection of seeing other people surviving and sharing their stories and struggles how they contracted it just making their voices be heard (Participant 6).

From the research findings, although participants were at different stages in their journey and had varying struggles, resiliency had impacted on participants' self-care in many different forms such as: doing the work of an activist, acceptance and overall taking better care of self both physically and otherwise.

Giving Back/Activism. Of the seven participants interviewed, four of the participants were out to the public and were involved directly in HIV/AIDS advocacy and activism. This means that the participants were speaking publicly at forums related to HIV/AIDS such as rallies

or conferences sharing their experiences, actively participating in research and volunteering as a positive road warrior. The participants were volunteering on the front lines at agencies or support groups for people who are living with HIV. Some participants choose to become politically active, speaking in public forums, HIV marches, schools, community centers, and being very open about their health status. Some of the respondents were engaged in research, in addition to volunteering their time providing support for people living with HIV.

> . . . I wanted to let them know that you can survive you know you can you might be HIV positive but still you can live a full and healthy life . . . I wanted to encourage them [members of the community], provide support too because lot of time most First Nations are diagnosed with HIV that's the first thing they think: what is my family going to think, what is my family going to do, or whatever. So I wanted them to understand that its ok you know you can actually live with HIV, so I am always encouraging persons, and sharing my stories and experience to help them be better (Participant 1).

Acceptance. Acceptance was another component that ASO helped participants to reach. Acceptance of one's diagnosis and learning to live after HIV was an important component in the participants' journey. Participants acknowledged that self-acceptance was central to overcoming the negative effects of HIV/AIDS and the complexities of a stigmatizing disease.

> It really helped me look at my sexuality, like who I am and what I prefer you know, and really bring that forward . . . you being honest about being gay and you know First Nations and things like that. I think that's what really brings out that honesty about who I am. I started loving and accepting myself, now I am

> comfortable and have accepted my sexuality it's a part of me being happy, and living a fulfilling life (Participant 6).

Participant 5, she is learning to live life being HIV positive.

> I always wonder if people think I wake up one day and say I want to have HIV and that it would be great, and that I would love for my family to push me aside and treat me different, or that I would want to be alone not having someone beside me that will love me unconditionally . . . Hell no, I didn't choose that, it happened and now I am learning to live with it and just accept it (Participant 5).

Acceptance was also important for participant 1 on her journey.

> When you got it [HIV] you got it so you might as well accept it and just live life and be happy. I have learned that and that's what I'm trying to do every day. (Participant 1).

Taking better care of self. Participants reported being empowered and as a result is learning to take better care of themselves so that they can live healthier lives.

> The fact that I am actually for the first time really wanting to live, and I am taking steps to live a longer healthier life and that's one of the biggest changes in my life since I had it [HIV] (Participant 7).

Although participants had daily struggles with illicit drugs, they still strive to take better care of themselves.

> Being better able to take care of my self-knowing that I'm living with it and showing other people it is not the end of the world, you're a survivor . . . I take

> my positive diagnosis as a gift, since now I'm taking better care of myself. I do sometimes messed up with drugs and stuff, but I think I've always done that regardless of whether I have HIV or not, you know what I mean . . . the fact that I am a stronger person or I'm so much more healthier (Participant 5).

Taking better of one's self was a result of participant 1 resilient spirit.

> It has actually given me more strength being HIV positive, my life have a purpose . . . to fight doing the prevention work and everything . . . I have learned to don't give up, eating healthy, sleeping and being g positive is all a part of the cure (Participant 1).

In addition, for participant 6 thinking positive, and the help and support from PLN have resulted in a positive outlook, growth and positive changes overall.

> I got better housing, I got myself into low income housing and I started taking better care of myself and kept taking the meds . . . (Participant 6).

Summary

In summary, the findings reported in this chapter show that participants experienced stigma. In some cases, stigma was experienced as a result of enacted discrimination, while other cases involved fears of being stigmatized or even internal stigma where participant experience shame, or guilt. Some participants experienced stigma from family, friends, and even in the workplace amongst coworkers. The challenges facing individuals living with HIV are numerous, from disclosure issues, to drugs, the lack of relationship, mental issues, and limited financial resources. In light of these experiences, participants might respond in a positive or negative way. This study focuses more on the positive, and on the process of resiliency emerging from the experience of stigma. The responses reported by respondents in the study ranged from: being

optimistic having faith and educating self and other. The support that participants received from friends and family, and the ASO organizations had contributed to participants becoming more resilient. Participants also reported receiving support from family, friends, and trusted members of society who helped them to face stigma in a positive manner. Additionally, participants in the study also experienced growth and transformation as a result of their stigma experience. Participants shared how their knowledge and experiences led them to educate others and give back to society in the form of activism working with ASO organizations as volunteers, peer support worker, conducting HIV talks and seminars. Also, being resilient has positively impacted on participant's self-care acceptance and love of self.

Chapter 5: Discussion

The study used a phenomenological approach to examine the lived experiences of PLWHA in Prince George. The primary objective of this thesis was: to explore and highlight the lived experience of people living with HIV-related stigma in Prince George; secondly, to understand the impacts of stigma; thirdly, to identify ways in which those living with HIV/AIDS respond to stigma. In this chapter stigma experience and the challenges of the participants is discussed. This is followed by the theme of resilience and the factors that contributed to resiliency. The limitations of the study are then presented. This is then followed by the future research. The chapter ends with a conclusion of the study and implication for research.

Stigma experiences and challenges

It is clear from the data collected that stigma continues to be a pressing issue for those living with HIV. Three decades into the epidemic, stigmatization remains a core feature of the participant's experience of HIV/AIDS. Stigma experiences of the participants provided important insights in the experience of living with HIV and despite the increase in knowledge about the nature of the disease, stigma is still prevalent amongst PLWHA. Participants reported that family, friends and community members had tarnished views of them, discrediting them and this often led to feelings of loneliness and ostracism. In Goffman stigma theory, he believes that society rejects PLWHA as a result of their stigmatized attribute. Subsequently, this negatively impacts one's social identity, leading to social isolation, fears, and ostracism (Goffman, 1963). Participants in the study shared that other attributes such as their gender, sexuality, and race added to the complexity of their stigma experience and the ways in which they were treated by their family and friends. Such a result was expected given previous theoretical work indicating that HIV stigma is "layered upon," where stigma associated with homosexuality created a greater

burden of stigma for gays living with HIV (Lee, Kochman & Sikkema, 2002). According to Goffman, stigma is a special kind of relationship between attribute and stereotype and it is the process by which the reactions of others spoil normal identity (Goffman, 1963). Based on the findings, when participants learned about their diagnosis, it became a challenge for them to deal with the information. All participants shared common feelings such as shock, disbelief, panic, fear, guilt, shame and depression. After learning about their diagnosis, the participants had to integrate new information into their existing identity that translated into them questioning assumptions about many aspects of their life, rethinking their priorities and goals, knowing that their life would change. Similar findings of PLWHA experience of stigma were presented in other researches as well (Block, 2009; Florom-Smith & De Santis, 2012).

Additionally, stigmatized individuals were motivated to avoid negative situations with family and friends. Rather they preferred to create positive situations so that they would be able to cope with adversities introduced by HIV stigma. It was noted from the research findings that participants were not passive, but rather they were actively seeking to understand their social world. In addition, the findings also revealed that the lack of knowledge of the disease by family, friends and employers impacted on the lives of PLWHA due to fear of contracting the disease. Individuals shared stories of being rejected by family or treated differently by persons that meant the most to them (Block, 2009; Florom-Smith & De Santis, 2012). Similar findings were presented by Laryea and Gien (1993) where PLWHA shared traumatic experiences such as physical and emotional abuse, social isolation, fear and depression.

Other themes presented in this thesis centered on the participants' enacted and felt experiences of stigma. From the research findings, felt and enacted stigma posed threats to the participants' self-esteem, security and identity. Most of the participants reported that their

family members were not supportive, had limited knowledge of the virus which led to stigmatization resulting in loneliness, rejection and isolation. The findings of this research as well as existing research point to the need for educating employers, family and community organizations. Families and members of the communities should be counselled on how to be instrumental in helping persons living with HIV to empower themselves. In addition, it was noted that the participants living for longer period with HIV stigma learned various stigma management strategies in their daily interactions (Emlet, Brennan, Brennenstuhl, Rueda, Hart, Rourke & OHTN Cohort Study Team 2013). On the other hand, participants that were recently diagnosed experienced more anticipated stigma than enacted stigma. PLWHA fear stigma, because of the experiences of other persons living with HIV and this impacted on disclosure, access to services and being labeled as a 'deviant'. Comparable research findings showed positive correlation between time of HIV diagnosis, disclosure and coping (Tuffs, Wessell & Kearney, 2010). Based on these findings stigma at the societal level resulted in discrimination, distancing from family and friends and at the individual level it resulted in anticipated stigma and internalized stigma (Earnshaw & Chaudoir, 2009).

Given the stigma associated with HIV and the modes of transmission, there have been mild to severe negative consequences of HIV disclosure like discrimination, rejection and hostility (Remien and Milliens 2007). This study found that participants' feared social repercussions such as rejection, isolation, discrimination from disclosure of their HIV-positive status. As a result, participants selectively disclosed their seropositive status. Disclosure limited the breadth of social and emotional support particularly from family and friends. Hence, these findings are consistent with previous research that has found that HIV/AIDS stigma impacts testing, care, and disclosure of seropositive status (Chesney & Smith, 1999; Mason, Marks,

Simoni, Ruiz & Richardson, 1995; Varas-Diaz, Serranno-Garcia & Toro- Alfons, 2005). Similarly, it was noted that although disclosure was a painful process for the participant, disclosure to family and friends sometimes led to increase social support. These findings are consistent with other researches as well (Sowell & Phillips, 2010; Yoshioka & Schustack, 2001; Gilbert & Walker 2010).

When participants were asked about their experience of disclosing to family and friends, reactions to the news, as well as changes in relationships, participants' gave varied answers. Knowing the negative repercussions that disclosure would have, such as being identified and labelled, participants still chose to disclose their HIV status. A small number of the participants in this study revealed that disclosure of their HIV status resulted in a sense of empowerment and decreased stress. Similar results have been reported elsewhere (Tufts, Wessell & Kearney, 2010). Participants considered disclosure to be appropriate when it was done under safe circumstances, when they were in control, and comfortable with persons who needed the information. In addition, participants talked about the increased social support they received from family members, peers, and health providers. Comparable research had similar findings to Tufts and colleagues (2010). Participant 1 reported having a closer relationship with her father as a result of the support, love and encouragement she received. Related results have been reported in the literature by Chesney & Smith (1999), where individuals reported that acceptance and support from family and friends had resulted in greater closeness and overall improvement in their relationships.

In this study participants struggled to disclose their diagnosis, in response to felt stigma and the individuals that eventually choose to disclose, devised a method for disclosure (Block 2009; Scrambler 1998). For participant 6, disclosing his HIV was a difficult task so he opted to

keep it a secret for many years. He only disclosed his HIV status to his family when he became drunk. Disclosure for him meant accepting his diagnosis, and the various labels attach to being a person with HIV. Similar finding was presented in Emlet (2005), where the research participants avoided disclosing their diagnosis and went to great lengths to hide their serostatus.

Other challenges

Other challenges experienced by participants in this study included lack of jobs, mental health problem, lack of relationship and drugs. PLWHA reported experiencing depression due to loss of identity, loss of friends, anger, despair, lack of purpose and motivation due to the chronic nature of the illness. In this study, stigma resulted in poor mental health, depression and thoughts of suicide. Previous research has effectively identified and described HIV/AIDS stigma and its relation to mental illness (Herek, 1990, 1999; Herek et al., 2002; Scambler, 1998; Sigel &Meyer 1999). A common experience shared by all participants' in this study was loneliness, withdrawal, denial and fear of dying. Participant 2 shared, "There were times where it was very tough where I was borderline suicidal and there were some days I struggled with my internal feelings of having this disease." Similar findings were also presented by Sun et al., (2009) and Alpass & Neville (2003).

Another finding was limited finances due to unemployment. Having a job and being financially stable contributes to financial security, improved quality of life and the opportunity to create a social support system (Martin, 2011). Due to unemployment, participants had difficulties finding housing and other daily necessities, and this increased stress and vulnerabilities. From the experiences that the participants shared, limited finances led to frustration, hopelessness and at times depression. Participants in this study found it difficult to eat regular nutritious meals and at times lived in unsuitable living arrangements. These factors

resulted in stress, weakened immune system, low self- esteem and lower quality of life. Participant 2 shared that limited finances resulted in him being, "Stuck in low income housing and shelter" which impacted on his quality of life. These results from the study are consistent with the literature that link limited finances to PLWHA poor quality of life (Blalock, Mcdaniel & Farber, 2002; Ruedea et al., 2011).

An interesting finding from this study was the use illicit drugs as a coping mechanism. Drugs such as crack and pot was used by participants to alter the state of consciousness in order to recreate positive emotions and feelings (Ware, Rueda, Singer and Kilby, 2003). As result of the medications and the challenges of living with HIV, participants in the study experienced loss of appetite, nausea and mental health problems. Hence they used illicit drugs as a method to cope with daily challenges. Participant 7 shared that the side effects of her medication and other challenges impacted on her self -esteem, self-confidence, but pot and crack helped her to cope with the daily challenges of living with HIV. Similar finding was presented by Corless and colleagues, where individuals reported that the smoking of marijuana (pot) helped to increase their food intake, sleep measures, weight gain and overall it made them feel emotionally and physically better (Corless et al., 2009). Participants in this study reported that health care personnel were judgmental when PLWHAs were using illicit drugs for pain management. Participant 7 recounted, "They don't know the pain I'm going through, only I know and they judge me but if they won't give me [pain medications] I'm going to get pot." Therefore, there is a need to offer non-judgmental health care services and further studies to be conducted in the area of pain management and the use of traditional methods to relieve pain in PLWHA.

Resilience

Although living with HIV conveyed challenges such as stigma, poverty, and homelessness, participants gradually adapted to their situations over varying periods of time. A central theme of this study was resilience. The research findings indicated that participants responded to stigma in various ways such as optimism, educating one self, acceptance and hope. Their responses were impacted by various factors such their own internal resource, external factors such as family, friends, and ASOs. Based on findings, participants adapted to living with a chronic disease and learned how to self- manage and cope positively with their diagnosis. Comparable findings were presented in De Santis (2008) and Siegel &Meyer (1999). In this study, the strategies of resilience adopted by participants took on different forms. They drew on existing resources and expanded their positive emotions in order to alleviate their depression and shield themselves from felt or enacted stigma.

Major sub-themes of self-acceptance, feelings of belonging and finding purpose contributed to the participants' inner being or resilience core. Resilience core, according Wagnild (2010) consists of five essential characteristics: meaningful life (purpose), perseverance, self- reliance, equanimity and existential aloneness. These characteristics help individuals to respond to life's challenges with courage and emotional stamina, and is important in maintaining mental and physical health (Wagnild, 2010). Participants in the study shared that self-acceptance and purpose were important characteristics that helped them to move forward with their lives and the opportunity to reconstruct their life in the midst of adversity. Wagnild (2010) highlighted equanimity, a trait that describes individuals who are optimistic, was a key finding shared by most participants in the study. When faced with the fear of death and feelings of depression, participants were open to varying possibilities regardless of their situation.

Also, an important aspect of participant's resiliency was inner strength. Participants' reported that inner strength was having the capacity to build one self which helped them through challenging life events. As a result, participants viewed themselves as fighters or survivors rather than victims. Additionally, inner strength was important in helping participants to manage their illness, engage in positive behavior and live well. These findings were consistent with literature (Rotegard, Fagermoen & Ruland, 2011; Mendes, Roux & Ridosh, 2010) where participants' inner strength help them through difficult periods in their lives.

In terms of acceptance of one's diagnosis, selected participants in the study went through the various stages of grief before accepting the fact that they were living with HIV. The participants' process of acceptance involved an initial response of shock, anger which sometimes led to depression and denial. This is consistent with Smith, McCarragher & Brown (2014), who found that PLWHA went through various stages of grief. Smith et al. (2014) asserted that these stages of grief were similar to those described by Kubler-Ross, which included shock, anger, devastation, depression and denial before accepting their diagnosis. However, it should be noted from the findings that not all of the participants followed the same process in accepting their diagnosis.

In addition, a component that helps to empower individuals on their journey was spirituality or having faith. Spirituality provided some participants with meaning, purpose and it also helped in accepting their diagnosis (Younge, Salme & Bybee 2010). Faith in a God or a higher power provided comfort, hope, inner strength and optimism. Participant 7 indicated that her faith helped her not to give up and to believe that it was going to get better. She believed God had a purpose for life. Such results are consistent with research findings by Johnson, Elbert-Avila & Tulsky (2005).

For some participant, it has been a gradual process of coming to terms with their HIV diagnosis from an initial sense of hopelessness, they move to acceptance and adaptation, to redefining the meaning of HIV and finally seeing it as a condition that does not necessarily deny a relatively healthy and satisfying life. Going through this process helps them to gain a sense of control over their life, mobilize internal resources, redefine life meaning and purpose, and ultimately set new life plan (Siegel & Meyer, 1999). As a result of resiliency, participants had new personal goals that they wanted to accomplish, renewed commitment to life and personal growth. Participant 6, had renewed purpose, was going back to school, so as to obtain a college education with the possibility of finding a job and helping other PLWHAs'.

Support from Others

Resilience is access to external sources, and the findings from the study demonstrated that persons living with HIV have received numerous types of support from community members and organizations. Some participants shared that having the support of their family provided them with emotional support, unconditional love, and care. Maintaining connections with family and friends were crucial for PLWHA and this contributed to their sense of self, psychological wellbeing, and social competence (Sun et al., 2009). The support and love that participants received in this study resulted in them making better choices in the management of their disease, and feeling empowered. Participant 1 described, "My dad is my knight and shining armour and as long I got his love and support that's all I need. He is my everything." However, majority of participants did not receive any support from their immediate family and this was linked to a range of negative outcomes, including social withdrawal and loneliness, risk-taking behavior, increased risk and overall negative social and psychological outcomes. These findings

were congruent with other researches (Sun et al., 2009; Grov, Golub, Parsons, Brennan & Karpiak, 2010; Alpass & Neville, 2003).

A key finding of this research reported that all participants received support from PLN an ASO. Participants reported receiving emotional support from HIV support groups, as well as information on where to find the resources needed to cope with HIV related challenges. Additionally, participants also reported having received emotional growth and cultural appropriate services from PLN.

A central findings from this study was the need for belonging and forming positive lasting relationship which is a basic fundamental human need (Baurneister & Leary, 1995). Attending PLN, receiving support, and interacting with other members and staff helped the participants to form connections and provide them with a sense of belonging. PLN helped in the resiliency process by helping participants' to build capacity, nurture them, and foster their development. Most of the participants in the study did not receive much support from family or friends, therefore the support from ASOs such as PLN played a crucial role in the participants' lives and helped them manage their illness. The participants stated that PLN created an opportunity for them to make new social bonds, participate in social activities, and find caring genuine individuals. A common thread that ran through the participants' stories was making social connection and feeling a sense of belonging. The participants expressed that having a sense of belonging impacted their overall physical, emotional and psychological health. These findings were similarly presented by other researches (Hagerty & Williamsm, 1999; Turner & Mclaren, 2011).

In addition, the social support received from ASO enhanced PLWHA's resiliency by helping the participants to regulate their emotions and solve their problems. PLWHA reported

that ASO played a vital role in helping them to calm their feelings of distress or develop strategies to respond to various challenges like helping to them find job and a place to live. Past research on the extent to which social support impacted on resilience showed that social support played a key role in the process of resiliency (Earnshaw, Lang, Lippitt, Jin & Chaudoir, 2015). This study underscores the key role of health care providers and ASO in promoting the physical and psychosocial wellbeing of PLWHA. This was evident as participants consistently reported that they felt safe, and saw the staff at PLN as family rather than workers (Emlet, Tozay & Raveis, 20010). Participant 1 spoke of times where she felt like giving up, but the emotional support she received at PLN helped her to cope with the daily challenges, and find meaning and purpose in her life.

Likewise, PLN empower individuals to improve their life and quality of living through educational programs and seminars to increase the participants' knowledge about HIV, by increasing access to online resources, training, workshops and research opportunities. In a study conducted by Brashers, Haas, Neidig & Rintamaki (2002) it was found that persons belonging to ASOs had greater knowledge of HIV treatment and greater HIV social network integration in comparison to individuals that were not attached to an ASO. Related findings were also presented by Crook, Browne, Roberts & Gafni (2005). The knowledge obtained played a key role in the participant's lives as four of the participants took on the role of activist educating individuals in rural communities, doing presentations at schools, and conducting research. As a result this improved participant's overall self-care. Participant 6 reported, "He has found a purpose in his life knowing that he is saving lives."

Research findings indicated that the majority of the participants considered themselves to be resilient. They also reported that they were survivors and they started to take better care of

themselves. Although participants considered themselves to be resilient it should be noted that resilience was not a static process. When a person endured hardship there was no guarantee that they would always be resilient as the context and the nature of the adversity would impact the response to challenges. Base on the literature, resilience was defined by three features, succeeding despite high risk, adapting and maintaining competence and adjusting and recovering from past negative experiences (Fraser, Galinsky & Richman, 1999). To the participants, resilience meant adapting, growing and learning from challenges, while accepting downfalls.

The positive responses that participants have in this study reveal empowerment over the illness and autonomy in their lives. For many of the PLWHA, the decisions to improve their lives involves more than taking medication and seeing doctors regularly to care for their illness. The stories of the participants testify to the types of positivity that can be produced despite negativity. Listening to the stories of the participants, it was easy to think of HIV as a death sentence, but for many of the participants, it was actually a life sentence. Individuals started living healthier lives because of HIV, and this helped to challenge the perception of PLWHA and HIV itself. The study participants came to see themselves as being the primary agents responsible for enhancing their quality of life and making changes to adjust and live long term with HIV. Despite the physical toll that HIV has on their bodies and the stigmatized perceptions attached to the illness, participants still felt they had control over their lifestyle.

Study Limitations

There are strengths and weaknesses inherent in this qualitative data. One advantage of qualitative data is the ability to analyze the value people place on every day interactions, which are not easily analyzed through quantitative means. This study benefitted significantly from the qualitative nature of the data because it allowed for probing, clarifications, and expansion of

themes pertinent to the topic of this study, which included discussions about stigma, discrimination, fear of rejection and resilience. Second, the respondents were recruited from community-based ASO serving PLWHA in Prince George. Participation was open to those interested in sharing their experiences and recruitment goals based on select characteristics, living with HIV and older than 21. However, the location of the community-based AIDS services organizations limits the geographic distribution of the study participants. Also, the research used a small sample size and this may limit the generalizability of the findings to HIV-positive populations in other regions. In addition, participants are members of PLN as such, their experiences of stigma, challenges and response will be different from other individuals living with HIV/AIDS where there is limited access to health care services and ASO. However, the purpose of the research was not to generalize the findings to a larger population, but to share the lived experiences of PLWHA and their responses to stigma. Hence, a small sample size enabled an in-depth investigation of this phenomenon.

Additionally, my inexperience as a qualitative researcher was another limitation. This could have impacted on the quality of the interview and analysis that was conducted. I tried to manage this issue by doing mock interviews with a more experienced colleague, and I constantly sought help from my supervisors for the analysis portion on thesis. I also kept field notes and this was very useful for my data analysis to help me identify my biases, opinions and help with the emergent themes from the data.

Future Research

The findings of this study offer possible avenues of future research. Firstly, the already stigmatized populations and conducting quantitative research testing the impact of resilience on the improvement of quality of life. Secondly, research should focus on already stigmatized

populations such as sex workers, gays and IDUs who require multi- interventions due to layered stigma. Future research with this groups is needed to understand the impact of layered stigma on accessing health care service, adherence of medication and support. Similarly, stigma remains a major challenge for PLWHA, therefore there is a need to evaluate stigma intervention program and strategies by the various health authorities.

In addition, resilience based approach can inform the development of targeted intervention, and this would build skills and capacities that facilitate successful negotiation of high risk environment for vulnerable and at risk people. The use of quantitative studies could analyze groups that are more or less likely to employ resilience in disease strategies and possible interventions. An important finding from the study was the use of recreational drug in coping with HIV. This contrast most research that focuses on the negative implications of drugs, and currently there is limited research that addresses the topic of recreational drugs such as pot and crack, and its use in pain management for PLWHA. This research was focused on PLWHA in Prince George, who are members of PLN, who are accessing the services available to them. As such, this study could be replicated with vulnerable groups such as IDUs and men who have sex with men living in northern rural communities that have limited access to ASO services. This is to help better understand their needs and the challenges they face. Finally, ASO plays a vital role in HIV care and prevention and offers pivotal services to PLWHA. Thus developing research study to evaluate the effectiveness of ASO in meeting the needs of clients and ways in which they can improve services and access to clients.

Summary

This chapter presented the discussion of the study. The chapter was organized by discussing the themes that emerged from the findings that answer the research questions. The

major topics covered were stigma experiences of the participants, challenges and resiliency. In terms of stigma experiences of the participants, the themes that emerged from the participants' stories were enacted and felt stigma. The major challenges reported and discussed by participants were the lack of job, drugs use, mental health problems and lack of relationship. In addition, the topic of resilience was also covered. The themes that emerged from this study were internal strengths, support from family, friends and ASO. Finally, the limitations and future studies were also presented in the chapter.

Implications for Practice

Based on the findings, some broad conclusions can be drawn from the study about the lived experiences of the participants. Although these conclusions cannot be applied to every PLWHA in Prince George, or in Canada, the findings can nevertheless be used in similar circumstances. The findings point to the need for better understanding of the role of social interactions in the stigmatization process. An important aspect of stigma research is the intervention and development of programs that effectively address stigma and its consequences in the lives of PLWHA. Importantly, the implications of this study is the need to reduce HIV/AIDS stigma through the inclusion of education and prevention campaigns of PLWHA.

An important component for public health practitioners is using people infected and affected by HIV as resources as they will provide physical and emotional support to those newly diagnosed. The participants in the study talked about greater involvement in planning programs that meet their needs, and the use of social marketing to educate individuals about HIV and stigma. Participants shared that advertisements generally paint a negative picture of HIV, and is marketed as a deadly disease, highlighting the negative thus creating fear. However, participants wanted advertisements and programs that focused on PLWHA, living positively, sharing stories

of survival and victories, and their contributions to society. Also, the use of family and friends as counsellors and peer educators, to help those affected by HIV and are having a difficult time understanding the disease and ways to care for their family and friends.

In addition, a concern that was derived from this study was the lack of employment opportunities for PLWHA. Although PLN and other ASOs helped in finding jobs, individuals had limited educational knowledge which was a challenge. Counsellors and education officers in ASOs should offer career counselling and skills training for participants to better equip themselves for the job market. Currently, most PLWHA volunteer as peer educator but health authorities and ASOs could provide funding to educate and train PLWHA to work as peer counsellors and HIV/AIDS educator. This will provide employment opportunities as well as an avenue to share their experiences to those vulnerable and at risk, newly diagnosed and the society at large. In addition, these employment opportunities will provide PLWHA with an income, and reduce dependency on social service organization for food and clothing. Furthermore, provision of safe and secure housing for participants should be considered as a priority. This would create a sense of independence and improve self-confidence.

It is imperative to provide safe workplace environment, since stigma in the workplace was a major challenge for participants in the study. Employers in the work environment should provide HIV sensitization training so as to reduce stigma in the workplace. Also, disclosure continues to be a challenge for most participants and for person who are not attached to any ASO because of the fear of being recognized. ASOs should incorporate social media and other technological services for PLWHA living in the northern communities to access online counselling support services at their convenience. Service providers should also provide in home

services for persons who are newly diagnosed and afraid to visit a ASOs, as this would protect the anonymity of PLWHA.

What should health care providers, clinicians, health authorities learn from this research? Living with HIV and stigma are still important issues. Research funding should not only focus on the biomedical aspect of HIV, but it should also look at the social issues. Listening to the stories of PLWHA and their needs, and understanding how best to cater to these needs. The work of ASOs is a vital component in HIV care, therefore outreach strategies, should be continued and intensified especially in rural small communities.

Conclusion

In conducting this research, I have gained a deeper understanding of the experiences of PLWHA. In addition, PLWHA shared their stories of challenges, survival victories and determination. In sharing these stories, the participants used this medium to educate members of society about stigma and resilience, and the impact of stigma on their lives. Also, participants shared that there is much fear attached to HIV, and that society needs to accept that there is no shame living with HIV. Having HIV is not a death sentence.

This study focuses on three main objectives: firstly, to explore and highlight the lived experience of people living with HIV as it relates to stigma in Prince George; secondly, to understand the impacts of stigma; thirdly, to identify ways in which persons living with HIV/AIDS respond to stigma. Additionally, the long-term goal of this study was to add to a body of research and give voice to the subjective experience of HIV positive individuals' living in Prince George. By highlighting individual's experience, it was the aim of this research to gain an understanding of the lived experience of stigma. The research methodology used was

hermeneutic phenomenology. The research involved seven participants who shared their lived experiences of stigma and resilience.

The themes that emerged from the data were felt and enacted stigma, challenges, inner strengths, and support from family, friends and ASO. The experience of living with HIV/AIDS captured in this study led to the conclusion that HIV infection had a significant effect on an individual's day-to-day living, and stigma was a prevalent features in the participants' lives. As it relate to the themes of enacted and felt stigma, participants' were fired from their jobs, rejected by their family, friends and they feared stigma. These factors resulted in various challenges such as limited finances, lack of relationship, disclosure and substance use. Despite the adversity, participants adapted to these challenges with positive traits such as optimism, hope, determination and faith. Also, support from family, friends and ASO like PLN all contributed to the participants' resiliency and empowered them by building social relationship and providing supportive structures. This study gave an understanding of the role of PLN in building connections with participants and the impact it has participants' quality of life.

Although society might feel that persons living with HIV are victims, the findings painted a different picture, that participants are survivors. Participants endured hardship and struggles, but in spite of these daily challenges, participants are learning to live with optimism, purpose and determination. The findings of this study contribute to the field of HIV/AIDS by providing a medium to share the stories of PLWHA in Prince George, it also highlights the role of family, friends and ASOs in the process of resiliency.

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- Sign a letter of consent (in writing), thus giving permission to be interviewed. Also, verbal consent of participant to have the interview recorded on a digital voice recorder. Verbal consent of participants will be noted on the informed consent form by the researcher.
- Answer the researcher demographic questions and questions about their experiences with stigma, and their response to stigma
- Give consent to the researcher for the use of quotes and demographic information from your interview without using any personal information and thus protect your identity.

Potential risks to participants:

- There may be minor risk to participants of this study. These risks could include:
    - Concerns about confidentiality regarding their personal information.
    - Also participants could become emotionally upset because of the subject matter in question.
    - An additional risk is that participants may disclose information about harm to self or others, which will necessitate a report to authority.
- The Issue of Confidentiality will be addressed in the following manner :

    - Interviews will be manually or digitally recorded with the permission of the participants; only the researcher, paid transcriber (who will sign a confidentiality agreement form) and his two supervisors- Dr. Tina Fraser and Josée Lavoie (who are all obliged to respect your confidentiality) will have access to the information provided in the interviews;
    - The manual or digital recordings of the interviews will be kept in a locked filing cabinet in the researcher's school office 10-3028, and the voice recordings will be transcribed into computer files. The computer files and transcripts will be protected by password and firewalls. After my thesis defense the computer files and transcripts will be stored in a locked cabinet for a period of one year in the office of my supervisor Dr. Tina Fraser. After which the electronic/audio files, will be deleted and hardcopy will be shredded.
    - Any potentially identifying information will be removed or altered when input into the computer, a pseudonym will be used to identify participants in order to protect their identity;
    - There will be no identifying information included in the final study findings, however personal experience shared may be familiar to people you know;
    - The final study will be published as a thesis and possibly published in relevant journals, or presented at conferences. No information that could identify participants will be included in the final study;

- The risk of a participant becoming emotionally upset will be addressed as follows:

    - participants can decline to answer any questions that they choose not to answer, can decide to withdraw from the interview(and information given will be shredded), can ask that any information they provide be removed from the study

- At any time throughout the interview or after the interview, if participants are emotionally distressed he/she will be provided with a referral to the appropriate services that can provide counseling services.
  - Positive Living North – 1563 2nd Ave- (250-562-172)
  - UNBC Community Care Centre - 1310 3rd Avenue- (250-90-6457)
  - Northern Aboriginal HIV/AIDS Task Force -987 4th Avenue (250-562-3591)
  - Central Interior Native Health Society- 1110 4th Ave- (250-564-4422)

Benefits

There are many benefits to participating in this study that include:

- Participants will have the opportunity to reflect and share their lived experience their struggles and their victories with HIV and stigma. This may provide participants with a better understanding of their own needs in relation to these experiences, and help them to express those needs.
- Participants will have the opportunity to share their success in dealing with stigma and this information would be helpful, to people at risk and vulnerable of HIV/AIDS
- By sharing their experiences, participants will help this and other researchers have a better understanding of Stigma, and resilience in a Canadian context since very little research is conducted from this perspective.

By participating in this research, it is hoped that people will be more educated about stigma, and its impact, of stigma and thus using this knowledge to improve the knowledge and attitude, of individuals, community members' families and health care providers. Participants can request and receive a copy of the study from this researcher when it is completed. Should participants require any additional information or any questions at any time before; during or after the study they will be able to contact student researcher (Orlando McLeish) by email at mcleish@unbc.ca or cell phone at 250-640-3870, or my supervisors, Dr. Tina Fraser by email frasert@unbc.ca or by telephone 250-960-5714 or Dr. Josée Lavoie by email josee.lavoie@unbc.ca. If at any time there is any complains or concerns about the research project , please contact the Office of Research, University of Northern British Columbia 250.960.6735, or by email reb@unbc.ca. Additionally, although every effort is taken to protect the anonymity of all participants, anonymity cannot be guaranteed.

Appendix C: Research Informed Consent

Informed Consent

I understand that Orlando McLeish, a graduate student in the Master of Community Health Sciences Program at the University of Northern British Columbia, is requesting my participation in this research thesis that will examine the lived experiences of people living with HIV/AIDS in Prince George.

I understand that my participation in this study is voluntary and I can withdraw from the study at any time and that if I choose to withdraw from the study, my information will be destroyed immediately

I understand that the researcher will conduct an in-depth interview with me and that this interview will last approximately 90mins.

I understand that the researcher will ask questions relating to my lived experience of being HIV positive, including the impacts of my lived experience and how I respond effectively to these experiences.

I understand that the purpose of the research is to give voice to the experiences of stigmatized individuals living with HIV/AIDS, and their response to stigma.

I understand the attached information on the Project Information sheet, and I have received a copy.

I understand that the researcher will record information, and that the interviews will be digitally recorded. All the digital recordings will be password protected and only be accessed by the researcher, the transcriber (who signed a confidentiality agreement form), and my two supervisors Dr. Tina Fraser and Dr. Josée Lavoie.

I understand the benefits and risks involved in participating in this study.

I understand that I am agreeing to participate in this research study.

I have read or the researcher has read the project information sheet to me.

I understand that some of my actual words may be published in the written form, to capture the essence of my lived experience.

I have had the opportunity to ask questions, clarify any issues, and discuss the study with the researcher.

I understand that the researcher is obliged to maintain my confidentiality, and that no personally identifying information will be used in the thesis.

Appendix D: Demographic Questionnaire

Participant Demographic Questionnaire

Thanks for taking the time out to participate in this survey.

Pseudonym:_____

Age: _____

Gender:

☐ Female ☐ Male ☐ Intersexual

☐ Transgender ☐ Transsexual ☐ Two-Spirited

☐ Other *(please explain)* _____

Sexual identity:

☐ Bisexual ☐ Gay ☐ Heterosexual/Straight ☐ Lesbian

☐ Two-Spirited ☐ Transgender ☐ Transsexual ☐ Unsure

☐ Other *(please explain)* _____

Ethnicity:

☐ White/European ☐ Black/African/Caribbean
☐ East Asian/Chinese/Japanese ☐ South Asian/Indian/Pakistani

☐ Aboriginal/Métis/First Nations ☐ Middle Eastern

☐ Other *(please explain)* _____

Do you live in Prince George ? Yes ☐ No ☐

With whom or where do you live?

☐ On your own ☐ With parent(s)/step-parents(s)

☐ With a friend(s) ☐ With a sexual/romantic partner

☐ With a family member other than a parent/step-parent

☐ Foster home ☐ Hostel ☐ On the street

☐ Other *(please explain):* _____

What level of education do you have?

Elementary ☐ High School ☐ college diploma ☐ Bachelor's degree ☐ Graduate degree ☐

Are you employed? ☐ Yes ☐ No

If yes, what is your job? _____

How long Have you been diagnosed with HIV/AIDS

< 1year □ 1-5 years □ 6-10years □ 11-20 years □ > 21 years □

Appendix E: Interview Questions

Introduction

Thank you for participating in this interview. I greatly appreciate the effort and time taken to share your experience with me. In the process of conducting the interview, I will be asking open ended questions that will be addressing issues relating to your lived experiences, the impact it had on your response to your diagnosis and the ways in which you're responding positively to these experiences. Additionally, I will be asking questions relating to factors that have contributed to your successful handling of your experiences and its impact on your life living with HIV/AIDS. If at any point you do not understand the questions or you are unclear, please feel free to ask for clarifications. **You are under no obligation to answer all questions: if you feel uncomfortable with a question, please let me know and we can skip to the next one.**

Semi-structured interview questions

1.) Could you bring me back to the time of your diagnosis, (Probe where were you when you got the diagnosis, how did you feel, what was going on in your life at the time)

2.) Did you tell anyone about your HIV diagnosis? How have they responded? (Probe for categories of family members' friends, partners, service providers to your diagnosis? How did they react? Probe (partner, family, community).

3.) Tell me a time in your life that you felt people treated you differently or you felt differently because of your HIV/AIDS diagnosis? How is it different from the way they treated you before? And how is it different from how they treat other people who are HIV negative? Is there a story you would like to share?

4.) How have you responded to negative treatments? Probe (any particular story you would like to share?)

5.) How has living with HIV/AIDS affected your coping skills and your life? Probe: fears, disclosure, access to health care, delayed treatments).

6.) What are you learning about how to cope? What positive changes is this bringing to your life with HIV? Probe what has helped you in the difficult times in coping, how did it helped? What factors contributed to these positive changes?

7.) What words of advice would you give to someone who has just been given the same diagnosis? What could they do to help themselves that you wish you had known?

8.) Is there anything else you would love to share? Thank you for your participation and sharing your life experiences with me.

Appendix G: Transcriber Confidentiality Agreement

Thesis Title: "Fighting back": People Living with HIV in Prince George.

Research purpose: This research is to give voice to the subjective experience of individuals living with HIVAIDS in Prince George. People living with HIV/AIDS who agreed to participate in this study are asked to share their lived experiences, and the impact of their lived experience on their response to HIV/AIDS diagnosis. Additionally, participants are asked to share how they are responding effectively to their experience and the impact this have on their life and living with HIV/AIDS.

I, _____, the research transcriber, agree to:

- Keep all the information shared confidential, by never sharing or discussing the contents of this research in any form or format with anyone, other than the Primary Researcher (Orlando Mcleish).
- Ensure the security of all research documents while in your possession.
- Upon completion of transcription, return all research information in any form or format.
- After completion of transcription and consultation with the primary research, erase and destroy all information regarding to the research that is not returnable to the researcher such as documents on the computer.
- I have read and agree to all the information.

Research Transcriber

_____	_____	_____
Name	Signature	Date

Primary Researcher

_____	_____	_____
Name	*Signature*	